Texas HIV Reporting by Name: 1999

Introduction

Although the Texas Department of Health (TDH) began accepting HIV reports by name in January 1999, the process for making this policy change began much earlier. This paper will focus on the activities and outcomes associated with preparing for and implementing HIV reporting by name in Texas. The first section, *An Overview of HIV and AIDS Surveillance Systems*, will briefly review the history of HIV and AIDS surveillance in Texas. The second section, *Preparing for Change*, will focus on activities carried out in 1998, with a special emphasis on the Community Consultation on HIV Reporting and addressing community concerns through educational efforts. The third section, *Implementing HIV Reporting by Name*, will focus on the nuts and bolts of the literal implementation of the system, including provisions for ensuring confidentiality and security of the reporting information, and includes an overview of the first year of data resulting from HIV reporting. The fourth section, *Initial Outcomes of HIV Reporting by Name*, will discuss trends in HIV counseling and testing in the wake of HIV reporting by name, and will provide an brief evaluation of the HIV reporting system's performance.

I. An Overview of HIV and AIDS Surveillance Systems

A. A Brief History of HIV Reporting in Texas

On January 1, 1999 the Texas Department of Health (TDH) began collecting reports of HIV infection by name. By that time, nearly 49,000 Texas residents had been reported with AIDS and over half of them, slightly more than 28,000, had died. TDH has been collecting information on AIDS cases by name since the early 1980's.

Texas first recognized the importance of tracking HIV infection, in addition to AIDS, in 1987, when the Texas Legislature made HIV infection a reportable condition. Between September 1987 and December 1989, HIV infections were reportable by age and sex only.

In 1989, the Texas Board of Health approved new regulations for reporting HIV infection. The data to be reported were changed to include: sex, race-ethnicity, county of residence, date tested, and month and year of birth. Only first-time HIV diagnoses, made by a physician, and based upon acceptable laboratory test results, were to be reported.

Core Public Health Functions

Preventing the spread of diseases and epidemics

Providing leadership, health policy development, planning and resource management

Monitoring and evaluating health programs

Providing risk communication

Providing clear, useful, readily understandable information on health issues

Providing epidemiologic investigations of public health risks

Providing disease and health status surveillance

Linking people to needed personal health services

Assessing and reporting state, regional and local needs

Maintaining a non-proprietary, objective repository for public health data

Collecting and using outcome data to change and improve health status of population.

In 1992, realizing this HIV reporting system did not support many core public health functions, TDH proposed a named HIV reporting system to the Texas Board of Health. At that time, some communities raised confidentiality concerns regarding named reporting. In response, TDH considered and adopted an experimental numeric-based unique identifier (UI) system for HIV reporting.

Reporting of confirmed HIV infections by UI for adolescents and adults began in March 1994. Both test providers and laboratories were required to report four pieces of information to construct the UI for each individual with a confirmed HIV infection. Names were not included. TDH was aware at the

time the UI system was adopted that it was unlikely to support several core public health functions.² In theory, however, the UI system should have been able to provide sound epidemiologic data, thus allowing other core public health functions to be fulfilled. At the same time the UI was implemented, Texas began a CDC-funded evaluation study aimed at assessing the quality of the UI surveillance system for HIV infection.

Evaluations of the UI system conducted from 1995-1997 showed significant performance problems. The system produced reports with missing information, and evaluation efforts estimated that the UI reports reflected only about 25% to 60% of the actual HIV infections diagnosed in the years between 1994 and 1997. These problems are described in greater detail in a report entitled Unique

¹Confirmed HIV infections in children 12 years of age and younger have been reported by name since 1994.

²Guidelines for Evaluating Surveillance Systems **MMWR** - 37(S-5) 1-18 Publication date: 05/06/1988

Identifier Reporting for HIV Infection Surveillance, available at the TDH website. These shortfalls, combined with the stunning effects of new treatments for HIV infection, convinced staff at TDH that it was time to approach the community with a recommendation for HIV reporting by name. This recommendation was based on a need to provide better data characterizing burden of disease for planning and resource allocation purposes, and the need to provide a public health safety net that would assure that individuals with HIV-positive antibody tests received their results and they (and their partners) received appropriate referral and linkages to care. TDH made its recommendation for a system of HIV reporting by name in late 1997 with the distribution of the Unique Identifier Reporting for HIV Infection Surveillance report. It should be noted that these recommendations included a provision for the continued availability of anonymous HIV testing. In fact, Texas law requites that anonymous testing be available throughout the State, and TDH policy requires that providers contracting with TDH to provide HIV counseling and testing offer all clients the option to test anonymously.

In early 1998, the TDH Bureau of HIV and STD Prevention issued a position paper calling for changes in TDH morbidity reporting rules to include the reporting of names for individuals with newly diagnosed HIV infections. Over the course of 1998, Bureau staff held a series of public town hall meetings in different areas of the state to discuss issues raised in the white paper. After an additional formal publication and comment period on the proposed new reporting rules, the TDH Board of Health approved the rules in November 1998, opening the way for implementation of the new system on the first day of 1999. For months prior to and after the Board's approval of the rules, the Bureau sought input from affected communities on how best to implement the new surveillance system.³

³The HIV Reporting Community Consultant's Group, comprised of a wide variety of persons affected by the new morbidity reporting rules, met 6 times between July 1998 and November 1999. A list of participants is included in the appendix. approved by the Board of Health.

B. What is Public Health Surveillance?

Public health surveillance is the method that is used to gather specific information on different reportable conditions and diseases. Surveillance is the ongoing, systematic collection, analysis, interpretation and dissemination of health data. There are three basic categories of surveillance disease reports: a) those in which information is collected on each individual with the disease, condition or injury; b) conditions for which only the total number of patients seen is reported; and c) conditions for which the total number of cases is reported if, and only if, there is judged to be an epidemic. Most health jurisdictions have laws that specify which diseases, conditions or injuries are to be reported, who is responsible for reporting and what method and timing of reporting is to be used (e.g., by telephone within 24 hours of diagnosis or by mail within one week of diagnosis). The information required to be reported and the diseases that are mandated as "reportable" vary from state to state (and sometimes are different in large local health department areas). The Texas Department of Health rules concerning the reporting of communicable diseases specify 53 different diseases that require reporting of confirmed or suspected cases, among them HIV infection and AIDS.

Excerpts from CDC Recommended Surveillance Practices

Programs should collect a standard set of surveillance data for all cases . . .

CDC advises that . . . surveillance programs use the same confidential name-based approach for HIV surveillance as is currently used for AIDS surveillance nationwide

HIV and AIDS surveillance should be used to identify rare or previously unrecognized modes of HIV transmission, unusual clinical or virologic manifestations, and other cases of public health importance

HIV and AIDS surveillance should result in collection of data from all private and public sources of. . . testing and care services

Laboratory. . . surveillance methods . . . require follow-up with the provider to verify the infection status or clinical stage and obtain complete demographic and exposure risk data

HIV-infected persons who are initially tested anonymously are eligible to be reported to CDC's HIV/AIDS surveillance database only after they have had HIV infection diagnosed in a confidential testing setting . . . and meet the HIV and/or AIDS reporting criteria

... HIV case surveillance should not interfere with HIV- prevention programs, including ... anonymous HIV counseling and testing

Both public and private providers should refer persons in whom HIV infection has been diagnosed to programs that provide HIV care, treatment, and comprehensive prevention case-management

Surveillance programs should conduct regular, ongoing assessments of the performance of the surveillance system . . .

C. Why AIDS Case Reporting Was Not Enough:

Historically, surveillance for HIV disease had been tied to the onset of AIDS. In the summer of 1981, the first accounts of an unusual immune system disorder were reported by the Centers for Disease Control and Prevention (CDC).⁴ Five people from New York and California were known to be affected. By mid-1982, the disease had a name: Acquired Immunodeficiency Syndrome or AIDS.⁵ Several hundred cases were reported by this time and many of these people had already died. In 1983 the virus that causes AIDS was discovered; soon afterwards, it became apparent that a person could be infected with the Human Immunodeficiency Virus (HIV) and transmit it to others long before developing any outward symptoms. Although the virus had been identified, a test to detect it was not available until mid-1985. ⁶

Years before it was possible to test a person for HIV infection, the emergent nature of the fatal and frightening disease made manifest the need for morbidity reporting systems in order to plan public health prevention and services programs and to allocate public health funding and resources. Since cases of the later-stage AIDS *could* be identified and counted, and HIV infection could not, AIDS became the standard bearer for HIV infection surveillance.

However, from a public health perspective, the advantages of tracking and profiling HIV are significant, as HIV infection marks the *beginning* of the disease process, in contrast with AIDS, which is a late-stage marker of disease progression. Moreover, due to the effect of new HIV treatments that became available in 1996, those states and territories that relied on AIDS case surveillance information alone to target HIV prevention efforts were presented with in an increasingly distorted picture of HIV-infected populations.

The new drug therapies introduced in 1996 caused a decline in AIDS case counts because they delayed the drop in T-cell counts and the development of opportunistic illnesses that define AIDS. The plummeting of AIDS case counts gave no indication of whether or not HIV infection was decreasing. Further, the treatment breakthroughs of 1996 changed the profile of AIDS cases: those individuals who were diagnosed with AIDS afterwards came to represent a population in which there

⁴Pneumocystis Pneumonia -- Los Angeles, *MMWR* 1981;30:250-2 (June 5, 1981); Kaposi's Sarcoma and Pneumocycstis Pneumonia Among Homosexual Men - New York City and California. *MMWR*. July 4, 1981/30:305-8.

 $^{^5}$ Current Trends Update on Acquired Immune Deficiency Syndrome (AIDS) --United States \pmb{MMWR} September 24, 1982 / 31(37);507-508,513-514

⁶ Provisional Public Health Service Inter-Agency Recommendations for Screening Donated Blood and Plasma for Antibody to the Virus Causing Acquired Immunodeficiency Syndrome *MMWR* January 11, 1985 / 34 (1);1-5

was either a lack of treatment or treatment failure. Thus, epidemiologic trends and profiles based on AIDS reporting became less and less representative of people living with HIV infection. All of this pointed to a decreased role for AIDS case data in monitoring the HIV epidemic and to the need to establish sound HIV infection reporting systems in order to target prevention and allocate resources.

Figure 1, AIDS Case Counts by Year of Diagnosis, shows that the number of AIDS cases in the White population declined after 1992. At the same time, the rise of African American cases slowed, as did cases among Hispanics. Much of the change from 1992 to 1996 can be attributed to prevention efforts, earlier forms of anti-retroviral treatment, and the varied prophylaxes for opportunistic diseases available at the time. Between 1996 and 1998 AIDS cases for all races and ethnicities fell dramatically because highly active anti-retroviral treatments became available, thus fewer people reached the point of having the low helper T-cell counts and contracting the opportunistic diseases that define AIDS.

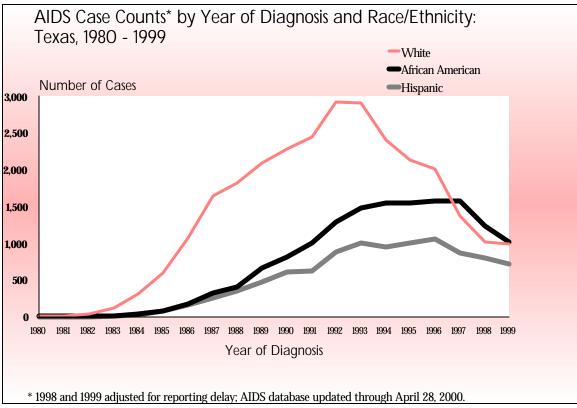


Figure 1: Texas AIDS Cases by Year of Diagnosis and Race/Ethnicity

II. Preparing for Change

A. The Community Consultation on HIV Reporting

Following the distribution of TDH's recommendations for name based HIV reporting, in early 1998, TDH sponsored a series of town hall meetings to gather reactions to the proposal. Core stakeholders in Texas were polarized on the issue of reporting by name. On the one hand, local public health authorities in the State were supportive of TDH's announced intention to pursue HIV reporting by name. The communities of infected and affected individuals, HIV advocates, and HIV prevention and services providers were largely opposed to the recommendations. These groups were concerned about confidentially issues, mistakenly believing that surveillance records would be subject to open records requests. They were also concerned about the possible deterrent effect of named reporting on HIV counseling and testing, and the possible loss of anonymous HIV testing options. Some of these stakeholders were also skeptical that this system would produce representative and reliable information about HIV infection in Texas.

Comments from the First Community Consult for HIV Reporting by Name

Taken from Notes from the First Meeting Held in Austin, Texas in June 1998

- i Epi people will be happy at the cost of many lives
- i Funding will be better distributed based on current HIV numbers not old AIDS numbers
- i (HIV reporting by name will lead to) decreased HIV testing
- i Surveillance programs will be overwhelmed initially
- i Cultures that have a deep-rooted distrust of Public Health Systems will have increased distrust due to named reporting. This will result in a continued health crisis in those populations
- i Immigration illegal immigrants will fear information exchange between government agencies
- **i** Voluntary partner notification will increase, increasing risk reduction counseling and entrance to early intervention
- i (HIV reporting by name will cause) an increase in anonymous testing at our clinic

In the face of these concerns, TDH chose to move forward with plans to change reporting rules, but asked community representatives to work with TDH on an extended basis to ensure that if HIV reporting by name were implemented, that communities be prepared for the change. It was hoped that this involvement would blunt any possible negative effects of the policy change, and it also offered an opportunity for TDH to better understand and address the communities' concerns and perceptions on this issue. TDH submitted the initial draft of the rule change to the Texas Board of Health in the early summer of 1998.

The Community Consultation on HIV Reporting was formed in the summer of 1998, and, with varying membership, met throughout 1998 to discuss issues associated with community reactions to HIV reporting. The group was made up of public health workers from local and regional health departments, HIV prevention and medical/social services providers, advocates, members of HIV Prevention Community Planning Groups and Ryan White HIV Care Consortia/Planning Councils, and individuals living with HIV/AIDS. The majority of the members of this group did not agree with HIV reporting by name, but agreed to work with TDH as a scenario-based strategic implementation group – meaning that all members agreed to work and discuss matters assuming that the Texas Board of Health would approve rule changes to allow HIV reporting by name. Therefore, the meetings and discussions of the group were not devoted to whether HIV reporting was desirable, but focused on what the rule change would mean for their communities, and how to prepare their communities and clients for the change.

Over the months the group met, they carried issues raised by members of their communities to the table. The group also discussed the content of the proposed rules, and recommended changes to certain provisions within the rules, some of which were incorporated by TDH when the rules were revised and submitted to the Board in x of 1998. The group meetings also provided a forum for correcting misconceptions about HIV reporting, and for the group members, most of whom were not from public health backgrounds, to better understand how HIV surveillance would work and howsurveillance fits into the overall public health system. This included discussions of public health surveillance practices, disease intervention activities, and STD program activities and policies. Meetings continued throughout the public comment period on the rules.

The timing of the rule submission meant that if the Board were to adopt the rules proposed by TDH, that adoption would occur in late 1998, to become effective January, 1999. In the fall of 1998, the group worked with TDH to produce an information packet to be released as soon as the Board's decision was announced preparing the way for implementation of HIV reporting by name in 1999. The packet materials covered frequently asked questions about HIV reporting, and placed special emphasis on security issues, confidentiality of reporting information, the continued availability of

anonymous testing, and gave detailed instructions for providers and laboratories on how to report HIV-positive test results. These materials were widely distributed, and were placed on the TDH web site.

The group was also instrumental in arranging local meetings of providers in early 1999 to discuss the rule change, and providing training for providers on how to report HIV infections. These forums served as an opportunity to the community to ask questions of both State and local health department staff on reporting procedures and protections. As will be seen in later sections, HIV reporting was implemented smoothly in Texas, without disruption of local prevention efforts. This was due in large part to the dedication of the members of the consultation group (Appendix 1), and their willingness to provide reassurance and address misconceptions about the policy.

B. Preparing HIV Reporting Procedures

Early in 1998, the STD and HIV program managers in Texas met to discuss the implementation of HIV reporting by name. This group represented 11 HARS surveillance sites and 12 STD only surveillance sites. These managers formed five workgroups to begin to draft surveillance guidelines specific to HIV reporting by name. Workgroups addressed such items as security issues, routing of case reports and adjustment of workload to absorb HIV case investigations. Surveillance guidelines were discussed throughout the year and were finalized in late 1998. The HIV surveillance guidelines were also updated in early 2000 to reflect the change in procedures needed to accommodate the CDC case definition change for HIV infection that included detectable viral load tests.

Security has been and continues to be a major emphasis for surveillance programs. In preparation for the implementation of HIV reporting by name, security site visits were scheduled and performed for each of the 23 surveillance sites. These were comprehensive security visits and included a physical review of the security of the building and files and a review of the computer and network security utilized for HIV surveillance activities. Reports were provided back to the sites documenting the site review results. Unannounced security site visits were performed during the summer of 1999 to ensure that security measures were being maintained and that surveillance sites were conforming to security recommendations.

III. Implementing HIV Reporting by Name

A. Assuring Confidentiality and Security of Surveillance Records

In order to protect the security and confidentiality of HIV and AIDS case reports and surveillance databases that contain potentially identifying data, the Bureau of HIV and STD Prevention at the Texas Department of Health (TDH) has taken specific proactive security measures at the central office and require a similar level of security and confidentiality at Regional TDH Offices and the offices of surveillance contractors, which are primarily local health departments.

- i All paper copies of data collection forms containing potentially identifying information are maintained in a locking file cabinet located in a locking file room.
- i All diskettes received from surveillance sites are password protected.
- i Diskettes provided by sites are either permanently erased or returned after being loaded and verified as erased.
- i Access to the surveillance databases are limited to the fewest numbers of staff possible and only to those employees that have an express need to use the surveillance databases.
- i Offices which house surveillance data have physically restricted access.
- i Telephone conversations in which staff must use or discuss patient identifiers or other confidential information are made in secure areas.
- i All paper copies or computer discs that must be hand carried are kept in locking briefcases that the staff member maintains with them at all times until it can be secured in a locking cabinet and secure environment.
- i Any state or local presentations of data, oral or written, includes only aggregate data with no identifiers.
- i All surveillance employees have received a copy of the Texas Communicable Disease Prevention and Control Act addressing confidentiality and penalties for breaches of confidentiality.
- i All surveillance employees are required to read and sign a Statement of Confidentiality

stating that they have read and understand the provisions of the act and the penalties including dismissal for any violation of confidentiality.

The Bureau of HIV and STD Prevention has been collecting named AIDS case reports for ten years and does not know of any breach of confidentiality that has occurred through the public health surveillance system.

Excerpts from CDC Recommendations on Security and Confidentiality

Electronic HIV/AIDS surveillance data should be protected by computer encryption during data transfer

States should continue the established practice of not including personal identifying information in HIV/AIDS surveillance data forwarded to CDC

HIV and AIDS surveillance records should be located in a physically secured area and should be protected by coded passwords and computer encryption

Access to the HIV/AIDS surveillance registry should be restricted to a minimum number of authorized surveillance staff, who are:

*designated by a responsible authorizing official

* trained in confidentiality procedures

*aware of penalties for unauthorized disclosure of surveillance information

Other public health programs that receive HIV/AIDS information . . . should have security and confidentiality protections and penalties for unauthorized disclosure equivalent to those for HIV/AIDS surveillance data and personnel

HIV and AIDS surveillance data made available for epidemiologic analyses must not include names or other identifying information

... Data release policies should ensure that the release of data for statistical purposes does not result in the direct or indirect identification of persons reported with HIV infection and AIDS

B. The Epidemiology of HIV and AIDS in Texas

1. Populations

Population values and percentages are given in order to provide the reader with a context for many of the statistics on HIV (not AIDS) and AIDS in 1999, which follow. The Texas population of adults and adolescents age 13 or older has grown: since 1980, the estimated number in this segment of the population has increased by slightly over 42%. Hispanics and Others (Asians, Pacific Islanders, American Indians, Native Alaskans) have had a greater rate of increase than have African Americans or Whites, thus they constituted larger proportions of the population in 1999 than they did in 1980.

Note that among Texas residents age 13 or older, females outnumber males by over 300,000; females make up 51% of this sub-population over the age of twelve. However, the pattern does not hold true for Hispanics: where males outnumber females by about 58,000. The inequality in sex ratio in favor of females is most pronounced among African Americans. Overall, the Texas adult/adolescent population is comprised of 58% Whites, 28% Hispanics, 11% African Americans, and 3% Other.

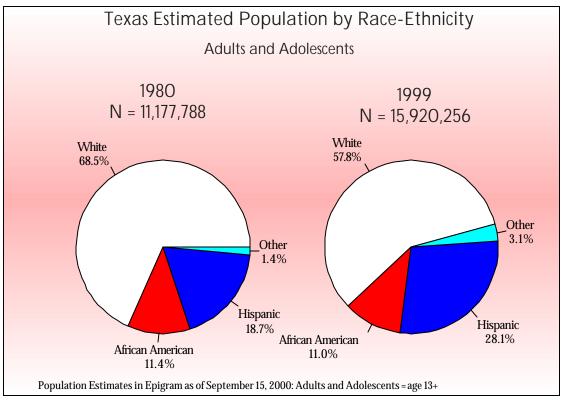


Figure 2: Estimates of Texas Population by Race-Ethnicity for 1980 and 1999

Table 1

Texas 1999 Estimated Population, Age 13+

	Males				Females	Total		
	Number	Percent	Percent	Number	Percent	Percent	Total	Percent
	Males	of	of	Females	of	of	Number	of
Race	in	All	Total	in	All	Total	in	Total
/Ethnicity	Population	Males	Population	Population	Females	Population	Population	Population
ļ								
White	4,462,673	57.2%	28.0%	4,737,288	58.3%	29.8%	9,199,962	57.8%
African Am.	823,236	10.6%	5.2%	922,369	11.4%	5.8%	1,745,605	11.0%
Hispanic	2,269,241	29.1%	14.3%	2,211,343	27.2%	13.9%	4,480,584	28.1%
Other	244,289	3.1%	1.5%	249,817	3.1%	1.6%	494,106	3.1%
Total	7,799,439	100.0%	49.0%	8,120,817	100.0%	51.0 %	15,920,257	100.0%

Population estimates taken from Epigram on 9-15-2000

2. Comparisons - HIV and AIDS

In these analyses, when we speak of HIV cases, we mean those people reported with HIV in a given year who had *not* progressed to AIDS by the end of that year. This makes the two categories (AIDS and HIV) mutually exclusive.

The year 1999 was the first year in which Texas adult and adolescent cases of HIV infection were reported by name. Results for 1999 from the AIDS surveillance system, established in the 1980's, are shown here for comparative purposes. When Texas began HIV reporting by name in 1999, TDH eschewed retroactive reporting, saying that under the current definition, it would neither seek nor accept HIV tests done before January 1, 1999.

Nearly as many HIV cases (2,840) as AIDS cases (2,855) were reported in the first year of the new surveillance system. The age distributions of HIV and AIDS cases reported in the same year are dissimilar. As would be expected, HIV cases tend to be younger than AIDS cases. The natural history of HIV infection predicts a considerable length of time between HIV infection and progression to AIDS. Thus, by its very nature, HIV surveillance would be expected to represent a younger population of HIV-infected people than AIDS surveillance. Because people are not usually

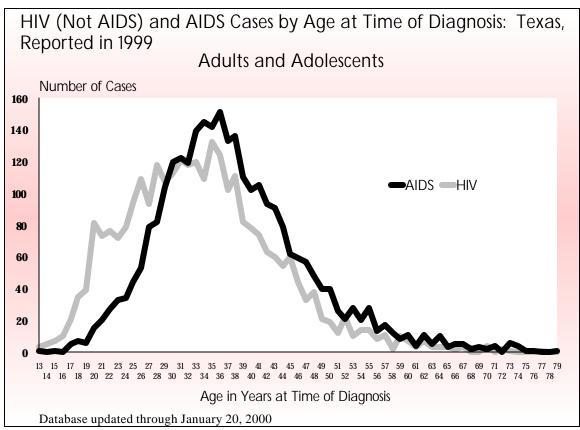


Figure 3: Age Distribution of HIV and AIDS - Age 13+

tested as soon as they are infected, we would not expect the age difference to be as pronounced as it would be otherwise. The curve for HIV cases is more "spread out" than the curve for AIDS cases (which advances and declines steeply at younger and older ages). Both curves tail off on the older side, most likely reflecting a generalized moderation of behavioral habits related to maturity that attenuates sexual and drug-use risks and thus attenuates HIV infection in this group.

The racial and ethnic distributions for AIDS and HIV differ slightly. AIDS cases reported in 1999 for people over the age of twelve show Whites constituted 38% of all cases; for similarly reported HIV cases, the White percentage was lower at 33%. A comparable attenuation in percentage is observed among Hispanics. However, among adults and adolescents, African Americans made up only around 37% of all AIDS cases, but they made up 47% of all adult and adolescent HIV cases.

When we look at 1999 adult and adolescent AIDS and HIV cases by sex, it becomes apparent that

a greater proportion of the HIV cases are women (around 31%) compared to the women's proportion of the AIDS cases reported in the same year (over 18%). Since the beginning of the epidemic, AIDS case percentages for males and females have been steadily shifting towards a ratio demonstrating a greater involvement of women, although HIV-positive men are still disproportionately affected compared to their number in the Texas population. Men make up 49% of the adult and adolescent population but they account for 69% of the 1999 HIV cases. Nevertheless, the gender discrepancy between AIDS and HIV cases reported in the same year indicates that HIV transmission has made steady inroads into the population of Texas adult and adolescent women.

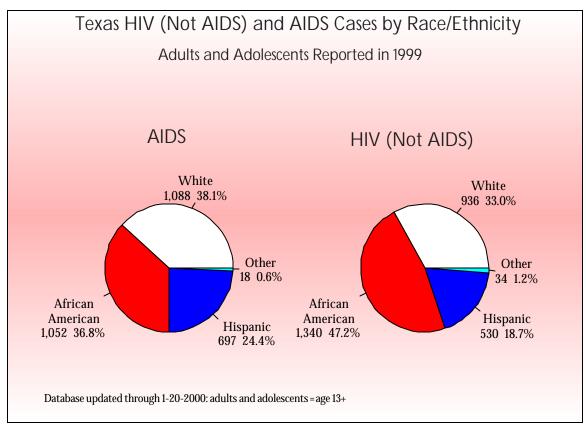


Figure 4: Texas HIV and AIDS Cases Reported in 1999 by Race/Ethnicity - Age 13+

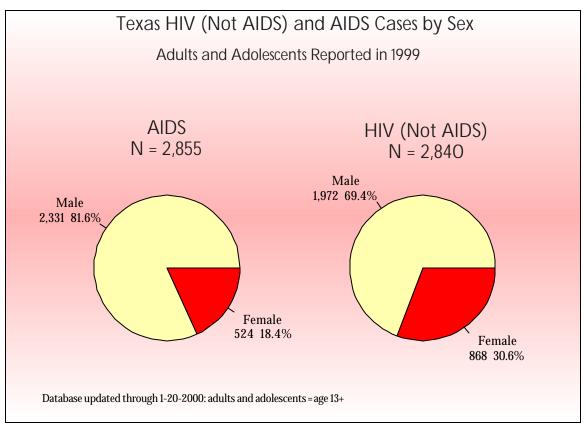


Figure 5: Texas HIV and AIDS Reported in 1999 by Sex - Age 13+

Table 2

Texas Adult and Adolescent Cases Reported in 1999

Race-Ethnicity by Sex

Paco	Race		AIDS Sex			HIV (Not AIDS) Sex			
Ethnicity	Statistic	Male	Female	Total		Female	Total		
White	Number of Cases % within Race-Ethnicity % within Sex	956 87.9% 41.0%	132 12.1% 25.2%	1,088 100% 38.1%	735 78.5% 37.3%	201 21.5% 23.2%	936 100% 33.0%		
African American	Number of Cases % within Race-Ethnicity % within Sex	770 73.2% 33.0%	282 26.8% 53.8%	1,052 100% 36.8%	812 60.6% 41.2%	528 39.4% 60.8%	1,340 100% 47.2%		
Hispanic	Number of Cases % within Race-Ethnicity % within Sex	591 84.8% 25.4%	106 15.2% 20.2%	697 100% 24.4%	398 75.1% 20.2%	132 24.9% 15.2%	530 100% 18.7%		
Other	Number of Cases % within Race-Ethnicity % within Sex	14 77.8% 0.6%	4 22.2% 0.8%	18 100% 0.6%	19 86.4% 1.0%	3 13.6% 0.3%	22 100% 0.8%		
Not Specified	Number of Cases % within Race-Ethnicity % within Sex	0 0.0% 0.0%	0 0.0% 0.0%	0 0.0% 0.0%	8 66.7% 0.4%	4 33.3% 0.5%	12 100% 0.4%		
Total	Number of Cases % within Race-Ethnicity % within Sex	2,331 81.6% 100%	524 18.4% 100%	2,855 100% 100%	1,972 69.4% 100%	868 30.6% 100%	2,840 100% 100%		

Table 2, entitled *Texas Adult and Adolescent Cases Reported in 1999: Race-Ethnicity by Sex*, shows the disproportion between male and female cases, but it also demonstrates that the imbalance between men and women was less pronounced in the African American population. In 1999, 770 (or 73%) of the African American AIDS cases were male and 282 (or 27%) were female. The imbalance shrinks even further when numbers and proportions for HIV are examined: 812 (or 61%) are male and 528 (or 39%) are female. Thus, at a total of 1,340 HIV cases, not only are the greatest number of HIV infections (unlike AIDS cases) being found among the African American population, but compared to the other racial and ethnic groups, an elevated proportion of African American HIV infections are being discovered in female members of the population.

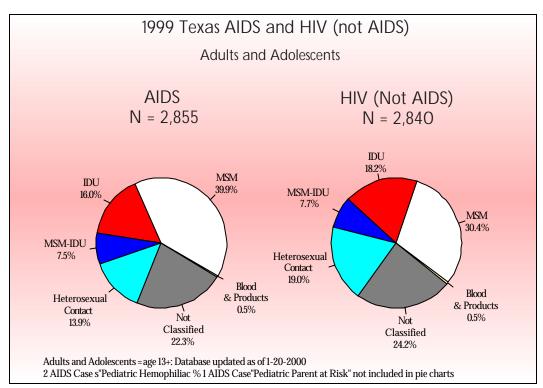


Figure 6: Texas HIV and AIDS by Mode of Exposure - Age 13+

When surveillance cases are first received, quite often the risk categories needed to determine the mode of exposure to HIV are missing. Note that for the 1999 reporting year, AIDS and HIV (not AIDS) cases had similar percentages of cases not classified (22 % and 24%, respectively). As the months and years pass and there is more time for field investigation of risks on this set of cases and they will be re-distributed from the status of not classified to one of the other risk-based mode of exposure categories.

Although it is difficult to predict the exact proportions that will appear on a chart of these 1999 HIV and AIDS cases done, say in the year 2003, it is noteworthy that the presumably more "recent" HIV cases (closer in time to the moment of HIV infection than AIDS cases), show a lesser proportion of the total HIV infections transmitted through Men Who Have Sex with Men (MSM) (30%) than is true for AIDS cases (40%). Conversely, for both sets of data reported during the same time period, heterosexual transmission is more prominent in the HIV cases, accounting for 19% of HIV and only 14% of AIDS cases. These two differences probably reflect the same trend that has been observed in a less striking form in AIDS statistics gathered over the last ten years.

Table 3

Texas Adult and Adolescent Cases Reported in 1999

Mode of Exposure by Race-Ethnicity

HIV (not AIDS)

Mode		Race-E					
of	White	African			Not	Total	Distribution
Exposure	Non-Hispanic	American	Hispanic	Other	Specified	Number	by Mode
MSM	406	263	187	8	0	864	30%
DU	155	283	77	2	0	517	18%
MSM-IDU	100	91	26	1	1	219	8%
Blood or Blood Products	8	5	0	0	0	13	1%
Heterosexual Contact	98	345	92	4	0	539	19%
Not Classified Yet	169	353	148	7	11	688	24%
Total Number	936	1,340	530	22	12	2,840	-
Distribution by Race-Ethnicity	33%	47%	19%	1%	0%	-	100%

AIDS

Mode	Mode Race-Ethnicity						
of	White	African			Not	Total	Distribution
Exposure	Non-Hispanic	American	Hispanic	Other	Specified	Number	by Mode
MSM	575	282	275	7	0	1,139	40%
IDU	134	232	89	1	0	456	16%
MSM-IDU	102	77	31	3	0	213	7 %
Blood or Blood Products	6	3	5	1	0	15	< 1%
Heterosexual Contact	85	209	99	3	0	396	14%
Not Classified Yet	186	249	197	3	0	635	22 %
Parent at Risk	0	0	1	0	0	1	<1%
Total Number	1,088	1,052	697	18	0	2,855	-
Distribution by Race-Ethnicity	38%	37%	24%	1%	0%	-	100%

 $Adult\ and\ Adolescent\ = Age\ 13+: HIV\ (not\ AIDS)\ = HIV\ Case\ not\ yet\ reported\ as\ an\ AIDS\ case.$ $Database\ Updated\ through\ 1-20-2000$

Men's and women's risk profiles differ considerably. The number of modes of exposure for categorizing men's risk is greater because it includes MSM and MSM and injecting drug use(IDU). Moreover, the pattern of exposure risks observed is different not only for men and women, but also for the *same* genders of different racial and ethnic groups. For example, although White women have had fewer reported IDU HIV cases in 1999 than have African American women (69 vs. 108) a

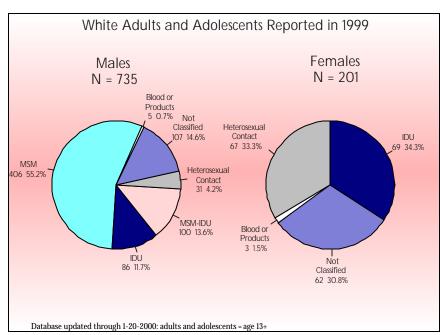


Figure 7: Adult and Adolescent Whites - 1999 HIV (Not AIDS)

greater percentage of White women's HIV cases were attributed to injecting drug use (34 % vs. 21 %). Women of different racial and ethnic groups vary between groups more than men in the ways they were exposed to HIV, mainly in the extent to which their reflect risks HIV transmission through injecting drug use or through heterosexual sex.

Note that in 1999, 812 HIV (Not AIDS) cases were

reported for African American men, but only 735 such cases were reported for White men. This is a reversal of the pattern seen over the years in AIDS cases. Hispanic men accounted for 398 such cases and men of other races and ethnicities accounted for only 19 cases.

African American men reported with HIV (Not AIDS) in 1999 were much more likely than White men to have no identifiable risk (NIR), with only 15% of the White male cases remaining in the NIR category, but with 21% of the African American male cases still unidentified as to the mode of their exposure to HIV. The difficulty of assigning risk increases even more with other minority groups: Hispanic males' proportion of NIR cases was 25% and Other males was 32%. Keeping in mind that more minority HIV infections remain in the NIR risk category, White men's proportion of MSM HIV cases is the only men's percentage to exceed 50%. Among males, African American men lead in both the number (176) and the proportion (22%) of their HIV cases attributed to injecting drug use.

Historically, it has always been harder to identify women's exposure risks, even for AIDS cases. The historical pattern is repeated here for HIV: 31% of White women's cases. 35% of African American. 36% of Hispanic, and 33 % of Other women's cases were NIR. The divergence between the number of reported HIV (not AIDS) cases for African American women vs. women of all otherraces and ethnicities is markedly pronounced, with

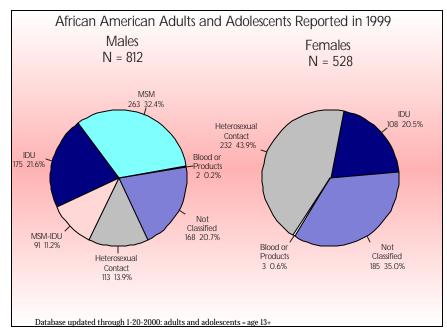


Figure &: Adult and Adolescent African Americans - 1999 HIV (Not AIDS)

African American women having more 1999 HIV (not AIDS) cases in 1999 (528) than all the other women's cases combined (Whites, 201 cases; Hispanics, 132 cases; and Other, 3 cases). This disparity underscores the severity of the problem of HIV/AIDS in the African American community in Texas.

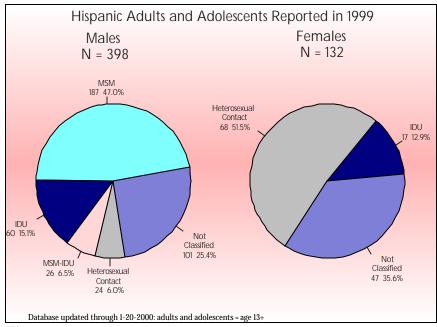


Figure 9: Adult and Adolescent Hispanics - 1999 HIV (Not AIDS)

Hispanic women's share of their total cases that are categorized as exposure to the virus through Heterosexual Sex is greater (52%)than those of White (33%) or African American (44%) women. Given the small number of Other women reported with HIV in 1999 (only 3 cases), the large percentage of Heterosexual Sex risks observed in this group is unlikely to be a particularly

reliable indicator of future trends in this group.

The ratio of female to male HIV cases among adults and adolescents varies widely by race and ethnicity. For each African American female HIV infection reported in 1999, there were only 1.5 African American male infections reported. The disparity between the numbers of mens' and women's cases widened for Whites and Hispanics: Whites had 3.7 mens infections reported for every female case, and Hispanics had 3.0 men's infections reported for every female case reported. The gap between men and women is more conspicuous among Texas residents of other races and ethnicities, with 6.3 male cases reported for every such female infection. (Note, however, that reports of HIV infection for Others are small in number, with a total of only 22 cases; this means that the sex ratio for Others may be less reliable than the ratios reported for Whites, African Americans and Hispanics).

At the beginning of the HIV epidemic, the only morbidity statistics available or even possible were those on AIDS. Before the virus that causes AIDS was discovered and before a test to detect the virus became available, it was apparent that an epidemic of cruel proportions was underway. Public health workers needed a way to count and characterize individuals stricken by the disease. Otherwise investigations into causes and plans for prevention would be chaotic and unorganized. Since it was possible to observe the *effects* of whatever was causing people to fall ill and to die all too quickly, the set of signs and symptoms we now recognize as late-stage HIV disease became the criteria for defining Acquired Immunodeficiency Syndrome or AIDS cases. Nearly two decades later, we need

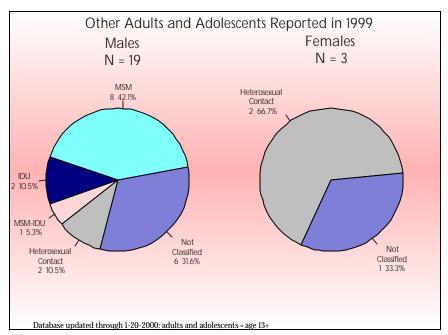


Figure 10: Adult and Adolescent Other - 1999 HIV (Not AIDS)

to acknowledge the continuity of HIV disease by accustoming ourselves to viewing statistics that combine HIV (not AIDS) and AIDS. Figure 7, Combined HIV and AIDS Cases by Public Health Region, gives that concept its due recognition.

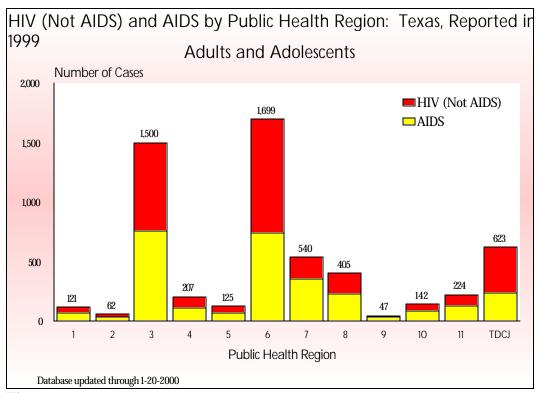


Figure 11: Combined HIV and AIDS Cases by Public Health Region

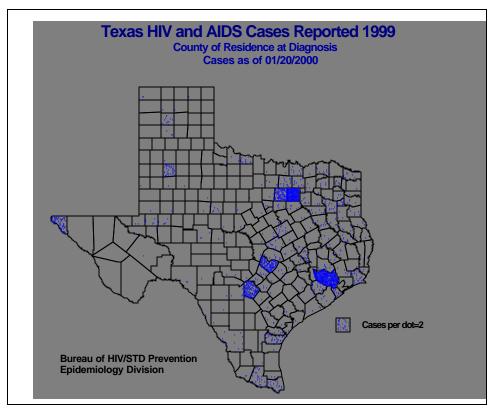


Figure 12: HIV/AIDS Cases Reported in 1999

The Houston area (Region 6) is still the most severely affected area of Texas, as it has been since the beginning of the epidemic. Following close behind is the Dallas area (Region 3), then prisoners in the state's Texas Department of Criminal System. Next comes the Austin area (Region 7) and the San Antonio area (Region 8). Note that the proportions of reported HIV to reported AIDS cases differ across public health regions. In instances where there are far fewer HIV cases than AIDS cases, the explanation is likely to involve reporting artifacts, not an actual lessening of disease in the area. Some regions were faster than others in implementing HIV reporting by name.

Reports of combined HIV and AIDS cases in Texas are predominantly from metropolitan areas. The largest number of adult and adolescent HIV or AIDS cases reported in 1999 were from Houston/Harris County (1,577) followed by Dallas (1,086), Austin/Travis (359), San Antonio/Bexar (357), Fort Worth/Tarrant (259), and El Paso (142) cities/counties. As featured in the map in Figure 12, 151 counties, (out of the 254 in Texas), reported at least one HIV or AIDS case in 1999. Tables of HIV and AIDS by Public Health Region and County of residence at the time of diagnosis are provided in Appendix 2.

3. Summary

- i 1999 HIV cases are, on average, younger than AIDS cases.
- i African Americans constitute a greater percentage share of HIV cases than they do of AIDS cases.
- i Women make up a greater proportion of HIV cases than they do of AIDS cases.
- i Heterosexual transmission of HIV accounts for a larger fraction of HIV cases than AIDS cases.
- i MSM transmission of HIV accounts for a smaller proportion of HIV cases than AIDS cases.

The pattern that emerges from these comparisons points to an HIV reporting system that is performing as one would expect if it was capturing more recent infections than those captured by the AIDS reporting system.

IV. Initial Outcomes of HIV Reporting by Name

A. Effects of HIV Reporting by Name on Publicly-Funded HIV Testing

One of the most frequently expressed concerns about HIV reporting by name is that it might drive people away from testing for HIV. Some were concerned that specific groups, such as gay men or African Americans, would be especially deterred from testing. Community members were also concerned that it would increase demand for anonymous testing, and since anonymous tests with positive results are not reported, that the new system would not provide information about the epidemic that was truly representative.

Over the course of 1999, TDH staff carefully monitored the information on HIV testing numbers and client profiles submitted by HIV counseling and testing contractors. Note that this does not represent all HIV tests done by private doctors and hospitals, or STD and other general public health clinics—but it does include more than 70 providers of HIV counseling and testing across all areas of Texas. Since these providers target groups in the community at highest risk for HIV for prevention services, if HIV reporting deterred testing it should be immediately apparent in this data flow.¹

¹ This information has been required of providers by TDH since the early 1990s, and so provides a good way to gauge if at risk groups are deterred from testing by this, or any other, policy change.

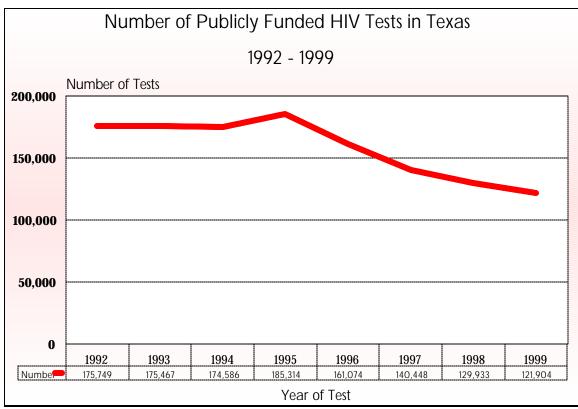


Figure 13: Number of Publicly Funded HIV Tests

1. Did the number of clients testing for HIV in publicly-funded testing drop in 1999?

There were 121,904 publicly funded HIV tests done in 1999, the first year of HIV reporting by name. This is a 6.7% drop from the number of tests done in 1998. But testing numbers have been dropping since they peaked in 1995. In 1995, there were 185,314 publicly-funded HIV tests. In 1996, tests dropped by 13.1%, in 1997 tests dropped by another 12.8%, and from 1997 to 1998 the number of tests done dropped 7.5%. **So when the overall testing trends are taken into account, HIV reporting by name did not appear to keep people from testing for HIV.** There have been bigger drops in testing seen in other years. In fact, the decrease in testing actually slowed down in 1999 compared to drops in the previous three years.

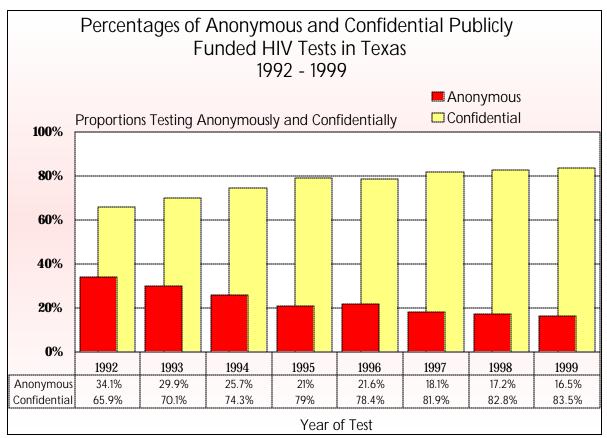


Figure 14: Percentages of Anonymous and Confidential Tests

2. Did more people choose to test anonymously because of HIV reporting by name?

Testing information shows that people were not more likely to test anonymously in 1999 than in other years. In fact, the percent of the total number of tests that were done anonymously has dropped over recent years. In 1992, about 34% of all publicly-funded HIV tests were anonymous. By 1995, that had dropped to 21% of all tests. By 1998 and 1999, about 17% of all tests were done anonymously. HIV reporting by name did not cause an increase in anonymous HIV testing.

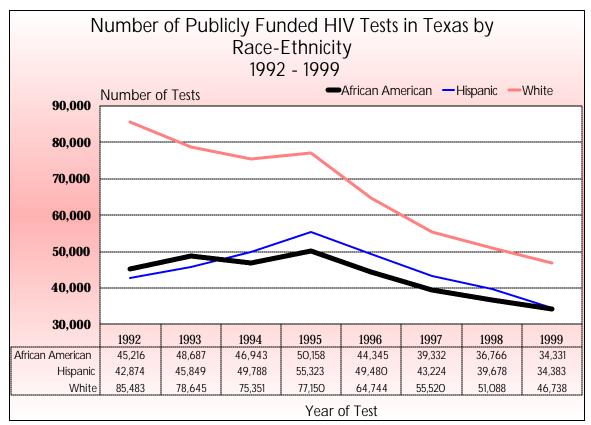


Figure 15: Number of Tests by Race/Ethnicity

3. Did fewer African Americans and Hispanics test because of HIV reporting by name? Did the race/ethnic backgrounds of those testing for HIV change in 1999?

In terms of total numbers of tests, declines were seen in all race ethnic groups – not surprising given the overall declines in testing. Over the years, however, the racial/ethnic profile showed minor changes with African Americans and Hispanics making up a slightly larger percentage of the total HIV testing. This trend did not change in 1999. In 1992, African Americans made up about 26% of those testing for HIV, Hispanics made up about 24%, and Whites made up about 49%. Over the years, African Americans and Hispanics made up slightly larger proportions of those testing for HIV. In 1998, the year before HIV reporting by name began, African Americans made up 28% of those testing, Hispanics made up 31%, and Whites made up 39%. In 1999, the first year of HIV reporting by name, African Americans and Hispanics made up about 28% each, with Whites making up 38%. The racial/ethnic profile of those testing at publicly funded HIV testing sites before and after named reporting is very similar. The slight decline in share of Hispanics testing may be due to the fact that 1999 was the first year that race and ethnicity were reported separately.

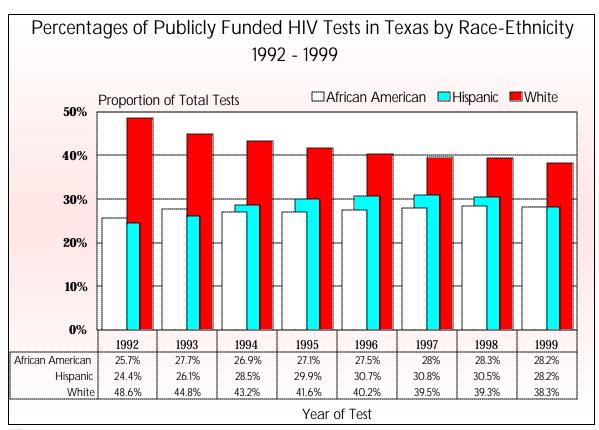


Figure 16: Percentages of Tests by Race/Ethnicity

4. Did anonymous testing go up in African Americans and Hispanics because of HIV reporting by name?

The percent of African Americans and Hispanics testing anonymously did not go up in 1999 compared to 1998. Over time, the percentage of people in all race/ethnic groups testing anonymously has decreased. These percentages were highest in 1992, when about 23% of African Americans and Hispanics tested anonymously and 45% of Whites tested anonymously. These percentages were lowest in 1999, when about 23% of Whites, 15% of Hispanics, and 9% of African Americans tested anonymously.

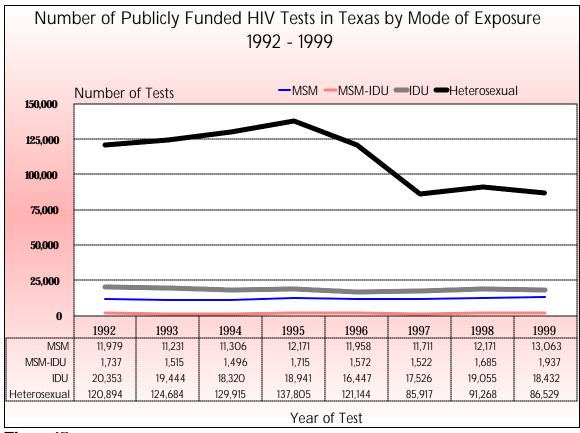


Figure 17: Number of Tests by Mode of Exposure

5. Did fewer gay men test because of HIV reporting by name?

HIV reporting by name did not seem to deter members of any particular risk groups from testing. The number of HIV tests among MSM actually increased by 7% from 1998 to 1999. The number of HIV tests for MSM and inject drugs also increased by 15%. Tests for IDU decreased by 3% from 1998 to 1999. Tests among heterosexuals declined by 5% between 1998 and 1999, but given the overall 7% drop in tests, this change does not necessarily show that heterosexuals were deterred from testing, but shows a decrease in testing that would be expected given historic trends for decreasing tests. The most dramatic declines in heterosexual test numbers occurred in 1996 and 1997, well before HIV reporting by name. If anything, the testing risk profile shows greater efforts at targeting individuals at highest risk for HIV testing. The biggest difference in the percentage share of risk groups from 1998 to 1999 was the decrease in the percentage of clients with no identified risk for HIV. The percentages of clients belonging to different risk groups was very similar from 1998 to 1999 – with MSM-IDU clients making up about 1.5%, MSM making up about 10%, IDU making

up about 15% and heterosexual clients making up about 70% of all clients getting an HIV test.

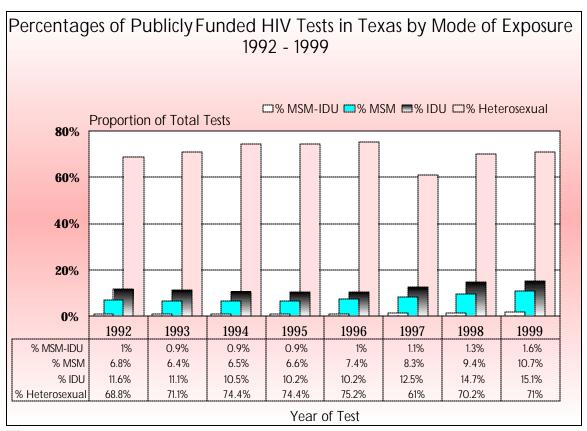


Figure 18: Percentage of Tests by Mode of Exposure

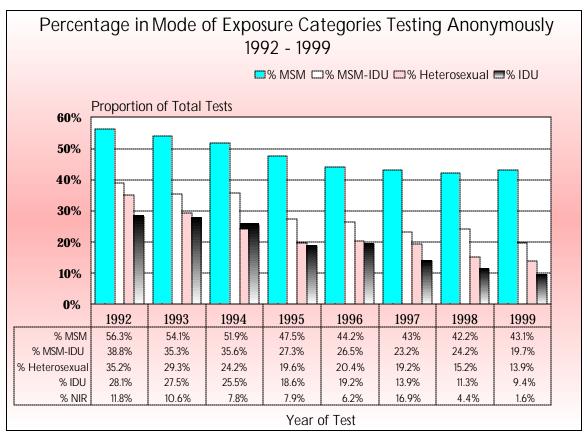


Figure 19: Percentages in Modes of Exposure Testing Anonymously

6. Did any risk groups show increases in anonymous testing because of HIV reporting by name?

All risk groups showed stable percentages of clients choosing anonymous testing in 1999, the first year of HIV reporting by name, compared to 1998. All risk groups have shown a decrease in the percentages of clients choosing anonymous testing when 1999 figures are compared to 1992 figures. MSM showed the highest percentage of anonymous tests across time, with 43% of MSM clients choosing anonymous testing in 1999. IDU showed the lowest proportion of anonymous tests, with 9% choosing anonymous testing in 1999.

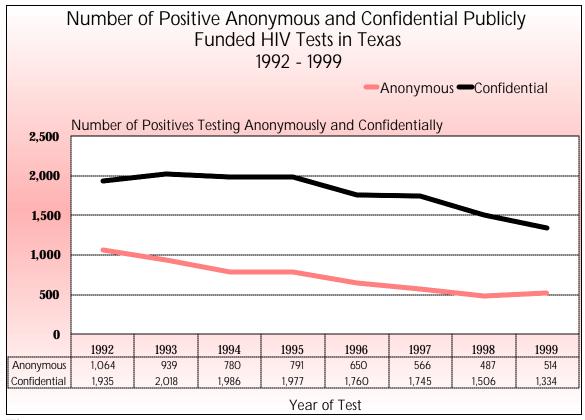


Figure 20: Number of Positives Testing Anonymously

7. Did people at highest risk avoid testing because of HIV reporting by name? What happened to the number of positive tests in 1999?

In 1999, there was a slight increase the number of positive anonymous test results, while the number of confidential positive test results showed a decrease. This means that in 1999, for every 100 confidential HIV tests done there were 1.3 positives, but for every 100 anonymous tests done, there were 2.6 positives.

For every 100 HIV tests done in 1999, there were 1.5 positive tests. This is exactly the same rate of positivity as found in 1998, which suggests that reporting by name did not deter positives from seeking HIV testing. Although the total number of HIV positive test results decreased by 7% from 1998 to 1999, there were larger decreases seen from 1995 to 1996 (13% drop in positives) and 1997 to 1998 (14% drop in positives).

However, the positivity rate for anonymous tests has been higher than the rate for confidential tests since 1992, with the difference becoming most pronounced from 1995 forward. This suggests that

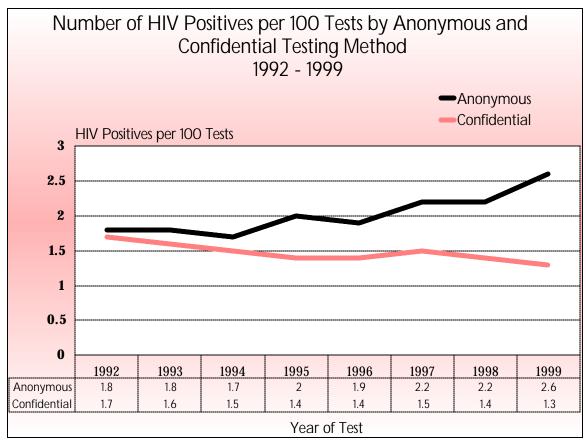


Figure 21: HIV Rate by Method of Testing

HIV reporting by name did not cause the clients at highest risk for HIV to switch to anonymous testing, since the difference in positivity rate appeared much earlier than the change to the reporting rules.

B. Evaluation of the HIV Surveillance System in the Initial Years of Implementation

1. Quality Assurance

HIV and AIDS cases are analyzed on a quarterly basis for Texas as whole and for each of the 13 major HIV/AIDS reporting (HARS) surveillance sites. Each local HARS surveillance site is provided a copy of the quality assurance analysis for its area, along with the same analysis for Texas. These reports provide the surveillance sites with a snapshot of "*How are we doing?*" and they alert sites that a high-level group at the TDH central office is routinely looking at their performance in a systematic way. Copies of the entire set of analyses for all 13 HARS sites and for Texas are distributed to members of the Bureau's HIV Reporting Evaluation Work Group, which includes the HIV/STD

Excerpts from CDC Evaluation Criteria for HIV/AIDS Surveillance System:

... state and local HIV/AIDS surveillance systems should use reporting methods that provide case reporting that is:

Complete (greater than or equal to 85%)

Timely (greater than or equal to 66% of cases reported within 6 months of diagnosis)

Accurate (less than or equal to 5% duplicate case reports and less than or equal to 5% incorrectly matched case reports)

... At least 85% of reported cases or a *representative* sample should have information regarding risk for HIV infection after epidemiologic follow-up is completed

Results in standard data collected in a reliable and valid manner

Allows matching to other public health databases to benefit specific public health goals

Allows identification and follow-up of individual cases of public health importance

States should also evaluate. . .

The potential impact of HIV surveillance on test-seeking patterns and behaviors

The extent to which surveillance data are being used for planning, targeting, and evaluating HIV-prevention programs and services

Epidemiology Division Director, three of the four Division Branch Managers, the Surveillance Coordinator, the Surveillance Contract Monitor, several epidemiologists, and field operations personnel. The reports provide the workgroup with a standard way to look for evidence of the quality of reporting practices on a site-by-site basis and permit group input to central office surveillance personnel who can then take action to improve data quality. The HIV Reporting Evaluation Workgroup meets every quarter. Semi-annual feedback reports to the local and regional surveillance sites began in 2000.

2. Measuring Completeness of Reporting

One way to measure completeness of reporting is to find an independent database (not used for HIV or AIDS surveillance) containing information on people who sought care for HIV or AIDS. Then, the HIV and AIDS data reported to the Texas Department of Health is compared to the independent database to see how many people were and were not reported as HIV or AIDS cases. In May 2000, a Memorandum of Agreement, based on the CDC, HCFA, and HRSA Model Data Sharing Agreement, was negotiated with the TDH Bureau of Information Resources (BIR), permitting us to access Medicaid client claims and prescription data as an independent data source, not normally used for surveillance case finding, to measure completeness of reporting. All data are being kept on the secure stand-alone HIV/STD surveillance network. Medicaid clients receive multiple services so they appear more than once in the data; therefore, in June 2000, claims were merged into a single file of about 17,000 unique Medicaid clients with HIV-related claims. Unique client records were subjected to fuzzy matching against HARS in July and August 2000. This will be a long-term project.

Another way to measure completeness of reporting is to go out and look at medical records in the offices of clinics, hospitals, physicians, and laboratories, among others. Then the HIV and AIDS cases reported to TDH are compared to the list of cases found in these record reviews out in the field. In late Spring 2000, we began a telephone survey of 1,194 laboratories in to determine what labs actually perform HIV testing. When the survey is complete, a random sample of labs will be chosen and asked to participate in a record review. The TDH Epidemiologist in charge of evaluating HIV reporting will travel to these areas to conduct the reviews. The aim of the reviews will be to measure the proportion of the labs's positive HIV tests (performed during the proper time frame) that actually were reported to TDH.

3. Measuring Completeness of Risk Information

One potential weaknesses of any surveillance system that depends heavily upon laboratory reporting is the lack of available risk factor information from that source. Unlike physicians, counseling and testing centers, and hospitals, laboratories do not need risk information to do their job, so they do not collect it. Initial reports that come in from laboratories have to be given special attention by local surveillance personnel to determine the risk(s) of the person reported as a case. Some states implementing HIV reporting have had difficulty in obtaining risk information for HIV

cases.² The lack of risk information on cases can be detrimental to planning efforts for HIV prevention, since much of that planning depends upon epidemiologic data for which the mode of transmission of HIV can be identified. Even though many states have had initial completeness of risk information percentages as low as 50%, and even though cases reported in the later months of 1999 have not yet had time for sufficient investigation to resolve cases with no reported risk, Table 4, below, shows that as of January 20, 2000, Texas 1999 HIV reporting completeness for risk stands at almost 76%.

Table 4

1999 Texas Adult and Adolescent HIV (not AIDS) Cases By Mode of Exposure						
Number Percent Mode of Exposure of Cases of Total						
MSM	864	30.4%				
IDU	517	18.2%				
MSM-IDU	219	7.7%				
Hemophiliac	2	0.1%				
Heterosexual Contact	539	19.0%				
Transfusion	11	0.4%				
Not Classified	688	24.2%				
Total	2,840	100.0%				

Adult and Adolescent = Age 13+: HIV (not AIDS) = HIV Case not yet reported as an AIDS case

Database updated through January 20, 2000

Compared to completeness of risk percentages for many states undertaking HIV reporting by name and compared to completeness of risk percentages for the previous unique identifier system used in Texas, the extent of cases with no identified risk is small.³

²CDC. Diagnosis and Reporting of HIV and AIDS in States with Integrated HIV and AIDS Surveillance -- United States, January 1994-June 1997. MMWR. April 24, 1998 / 47(15); 309-314

³CDC. Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers ---Maryland and Texas, 1994--1996, MMWR --- January 9, 1998 / Vol. 46 / No. 52 53

4. Measuring Reporting Delay

Using date variables in HARS, TDH analyzes the percentage of all AIDS cases reported within six months of their diagnosis date. The median number of months before cases were reported in 1999 was 2.68 months. Eighty-three (83%) were reported within six months of their diagnosis with AIDS. This is significantly less than reporting delays described in previous years.

The methodology for calculating a reporting delay for HIV (not AIDS) is currently under development. This has been complicated by the fact that, according to Texas reporting regulations, only HIV infection reports for which a test date documenting HIV infection that occurred **on or after 1/1/99** were *eligible* for reporting. For these *eligible* cases, surveillance personnel are asked to note the earliest known HIV test date in which the case had a positive result (if available) on the reporting form. Because of this, the traditional method of calculating reporting delay (the amount of time between the earliest known HIV test date and the date of report) over-estimates the true reporting delay. The apparent solution to the problem would be to calculate the time between the first *eligible* test date and the date of report. Remember, however, that this decision was made by Texas alone, not by most states. Therefore, the CDC HIV/AIDS Reporting system software that TDH uses to

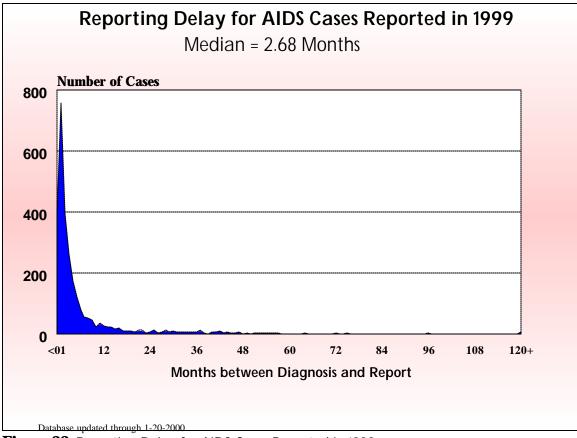


Figure 22: Reporting Delay for AIDS Cases Reported in 1999

mange HIV and AIDS reports makes no provision for an "eligible" date in a single field of the database. Instead the "eligible" dates are scattered throughout the database in over 20 different date fields. Although, thus far, the problem of consolidating them into one field that we can use to calculate reporting delay has proved refractory, we think this is a problem that can be solved when the epidemiologist/systems analyst doing this kind of programming can turn from other tasks to this one. Time constraints imposed by the need to write new code for various data management functions because of the commitment to not implement retroactive reporting of HIV-positive Western Blot tests and other first-line HIV tests has been the underlying problem, but it is one that eventually can be overcome.

5. Measuring the Provision of Services

One hallmark of a good surveillance system is that it can be used for more than just epidemiologic monitoring -- specifically, it should also be useful for getting people the care they need to deal with the disease. The first thing that has to happen to get someone into care is to make the person aware that they have tested positive for HIV. Table 5 shows that 92% of the adult and adolescent HIV (not AIDS) cases reported to TDH in 1999 were notified that they were infected. Two percent were not notified. The status of the other 4% is unknown (2% marked "Unknown" on the morbidity report and 2% left blank).

Once a person is informed of his or her HIV-positive sero-status, the next link in the chain is referring the person to various kinds of needed care: medical (including physician care, viral load testing, CD4+ testing, access to the available drug therapies), psycho-social support, transportation (if needed), early intervention, and prevention case management. Although morbidity reporting systems can only capture gross measures of this function carried out at the local level, 88% of the adult and adolescent HIV (not AIDS) cases reported to TDH in 1999 had the checkbox for referral filled in. Two percent were known to have *not* been referred, with the rest either unknown or blank. The character of the referral (medical, social, etc.) and the success of the referral remain unknown with these data. However, other data systems for HIV and STD Prevention and for HIV Services attempt to measure referrals in a much more detailed and complete fashion so they can track how well they are doing at the program level. This item on the HIV/AIDS surveillance morbidity report form is merely intended to give us an overview -- some idea of how many Texas cases are getting some kind of needed referral.

Table 5

Informing 1999 Adult and Adolescent HIV (Not AIDS) Cases

By Public Health Region of Residence of Case

	Patient Informed of HIV Infection?							
Region								
	No	Yes	Blank	Unknown	Total			
1	0	46	4	0	50			
2	0	28	0	2	30			
3	13	701	16	10	740			
4	5	89	4	0	98			
5	0	44	11	0	55			
6	16	876	17	46	955			
7	4	160	2	19	185			
8	0	142	25	7	174			
9	1	11	2	1	15			
10	0	54	1	0	55			
11	4	88	4	0	96			
TDCJ	0	384	2	1	387			
Total	43	2,623	88	86	2,840			
Percent of Total	2%	92%	3%	3%	100%			

Adult and Adolescent = Age 13+: HIV (not AIDS) = HIV Case not yet reported as an AIDS case Database updated through January 20, 2000

Another step needed to get people the care they need is to test the sex and drug-sharing partners of people reported with HIV infection. Then, if the partners are found to be positive for the virus, they too can get care for the disease and support in facing the trials it imposes. With the availability of effective treatments, partner notification has become an important activity—both to provide individuals with medication and to interrupt the disease transmission process. Table 7 shows the ways in which partners for 1999 reported adult and adolescent HIV (not AIDS) cases were expected to be notified. When people with HIV give their partner's names, they are permitted to choose the method of notifying those whom they might have exposed to infection. Around 29% of the adult and adolescent HIV cases chose to have their sexual partners or drug-sharing partners informed of their possible exposure by a health department representative. These representatives do not divulge

Table 6

Referrals for Adult and Adolescent HIV (Not AIDS) Cases Reported in 1999 by Public Health Region of Residence of Case

111 177	Patient Referred for HIV Services?						
Region					PHR		
	No	Yes	Blank	Unknown	Total		
1	0	30	6	14	50		
2	2	26	0	2	30		
3	13	665	43	19	740		
4	6	88	4	0	98		
5	1	38	11	5	55		
6	27	847	17	64	955		
7	4	156	6	19	185		
8	3	129	35	7	174		
9	0	11	3	1	15		
10	0	52	1	2	55		
11	6	82	5	3	96		
TDCJ	0	384	2	1	387		
Total	62	2,508	133	137	2,840		
Percent of Total	2%	88%	5%	5%	100%		

Adult and Adolescent = Age 13+: HIV (not AIDS) = HIV Case not yet reported as an AIDS case:

Database updated through January 20, 2000

the name of the possible source of transmission to the partner. Four percent of the HIV (not AIDS) cases chose to have their medical provider contact their partners. Thirty-six percent chose to tell their partners themselves. And, for nearly a third of the 2,840 cases, the person filling out the HIV/AIDS morbidity report did not know how partners were going to be informed, either leaving the item blank or indicating "Unknown." Not all people who are diagnosed with HIV are located and thus they cannot be asked about their partners; of those who are queried, not all are willing to give the names of partners. Some of the unknowns and blanks probably fall in these categories. For others counted as unknown or blank, presumably elicitations and notifications were planned, although the surveillance contact had no information concerning them.

Table 7
Who Will Notify Partners for Adult and Adolescent HIV (Not AIDS) Cases
Reported in 1999?

By Public Health Region of Residence of Case

		Partners Will Be Notified By?						
Region	Health Department	Physicia n- Provider	Patient	Blank	Unknown	PHR Total		
1	10	14	1	5	20	50		
2	6	0	12	0	12	30		
3	248	19	391	44	38	740		
4	36	11	43	5	3	98		
5	33	2	7	12	1	55		
6	328	37	442	17	131	955		
7	44	12	93	5	31	185		
8	80	2	10	65	17	174		
9	6	1	0	3	5	15		
10	2	1	2	1	49	55		
11	22	8	35	4	27	96		
TDCJ	3	0	0	2	382	387		
Total	818	107	1,036	163	716	2,840		
Percent of Total	29%	4%	36%	6%	25%	100%		

 $Adult\ and\ Adolescent\ = Age\ 13+:\ HIV\ (not\ AIDS)\ = HIV\ Case\ not\ yet\ reported\ as\ an\ AIDS\ case$

Database updated through January 20, 2000

Appendix 1: Participants in Community Consultation on HIV Reporting

Community Members

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> Robert Gerhardt El Paso HIV Consortium

> > Mitchell Gibbs Austin Habitat

Miguel Gonzalez Ryan White Planning Council, Houston

Louis Henry UT Southwestern AIDS Prevention Project

> Robert Herrera HAC, San Antonio

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Linda Hollins Houston Department of Health and Human Services

> Jim Howze Ryan White Planning Council, Dallas

> > Dorothy E. Lewis, Ph.D. Baylor College of Medicine

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Laurie McGill
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Tina Megdal Montrose Clinic

Mary Moreno Ryan White Planning Council, Austin

> Sylvia Moreno Parkland Hospital

Dennis Nelson David Powell Clinic

Gertie Oliver Over the Hill. Inc.

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Appendix 2: Statewide Epidemiology

One way of looking at disease is to count the number of people with the disease (as we did in Figure 1, *AIDS Cases by Year of Diagnosis and Race-Ethnicity*). Another is to calculate rates of disease in populations. To do this, we must have a good estimate of the number *in* the population. Rates are useful: they provide a measure of how intensely a population is affected by a disease. Figure 23, *Epidemic Intensity Among Racial and Ethnic Groups Over Time*, provides us with a longitudinal view of *when* and *how hard* Texas sub-populations were hit with late-stage HIV disease (or AIDS). By 1987, the AIDS case rate per 100,000 population for Texas African Americans exceeded the White rate. Although all rates declined once the new drug therapies became widely available, (and, due to prevention efforts and earlier forms of drug treatment, even before that for many groups) the African American AIDS case rate remained several times higher than the White, Hispanic, and Other rates in 1999.

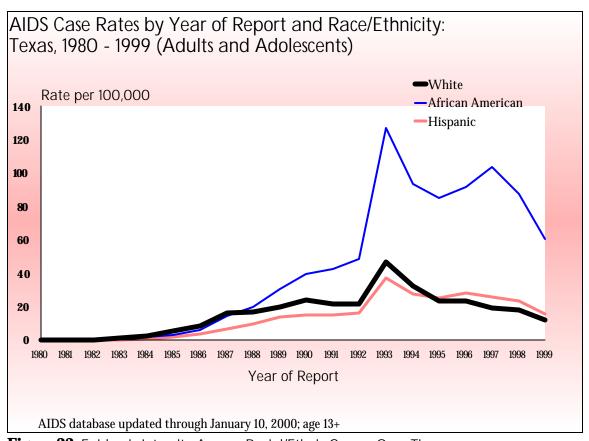


Figure 23: Epidemic Intensity Among Racial/Ethnic Groups Over Time

Figure 24 compares Texas 1999 HIV (Not AIDS) and AIDS case rates per 100,000 for the four sub-populations. Overall, the variance between race-ethnicity group rates is as we would expect from previous discussions, with African American rates much higher than those of other groups. However, for African Americans and Others, the HIV rates exceed the AIDS rate while the reverse is true for Whites and Hispanics. It is too early in the life of the new surveillance system to determine whether this is due to a reporting artifact or whether it indicates that, perhaps new HIV infections are declining among Whites and Hispanics.

Deaths in Texas directly caused by HIV infection have declined dramatically since the year of 1994 when over 2,750 people died of HIV/AIDS in one year alone. By 1998, that number had been reduced to fewer than 1,000.

As the number of deaths fell, more Texas residents were living with AIDS. Early in the epidemic, the rising level of AIDS prevalence was driven by the number of HIV infections occurring years before and by the 1993 CDC AIDS case definition change; more and more people were dying each year of AIDS, but the high HIV/AIDS death rates did not offset the effects of the number of new infections years before and the effects of the expanded definition of AIDS. After 1996, however, the picture became even murkier: AIDS prevalence levels now depend not only upon definition changes but also upon how many became HIV-infected years ago, how many have

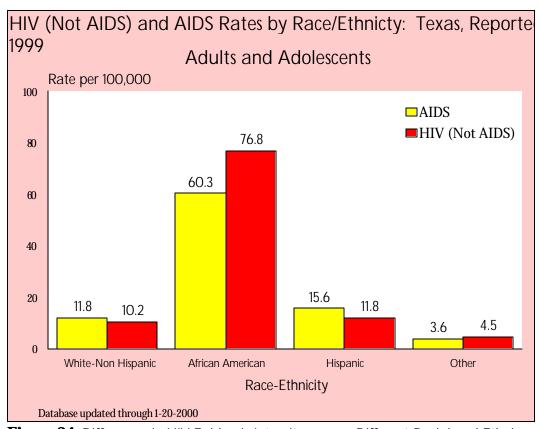


Figure 24: Differences in HIV Epidemic Intensity among Different Racial and Ethnic Groups

died, and how many have been prevented from reaching a CD4+ T-cell count of less than 200.

As mentioned earlier, the number of new AIDS diagnoses has been pushed downward by the life-and health-extending drug therapies. The availability of viable therapies has already led to better survival rates for AIDS cases (Figures 26 and 27). The cohort of people diagnosed with AIDS in 1992 did not fare well; less than 60% were still alive 30 months after they were diagnosed with AIDS. On the other hand, those diagnosed with AIDS in 1998, after the new drug regimens became widely used, fared better, with around 85 to 88% living at least for 30 months after their AIDS diagnosis. Eventually, however, the new therapies are expected to change not only the *number* of AIDS cases—as fewer people reach the low T-cell count or opportunistic diseases defining AIDS—but the *character* of reported AIDS cases. HIV-infected people whose CD4+ T-cell counts drop below 200 (AIDS cases) are increasingly coming to be viewed as either groups experiencing treatment failure or as groups without sufficient access to health care.

Appendix 3 contains graphs of HIV/AIDS deaths by Public Health Region and tables of living HIV and AIDS cases by Public Health Region and County of Residence at the time of diagnosis.

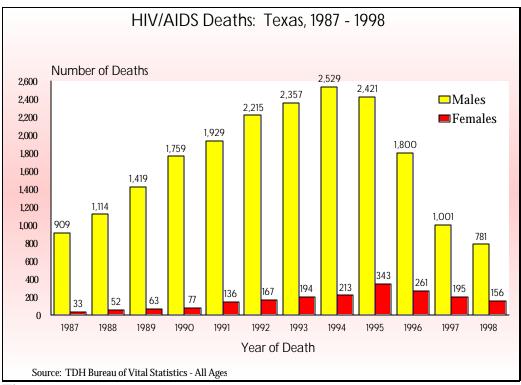


Figure 25: Texas HIV Deaths by Sex and Year of Death

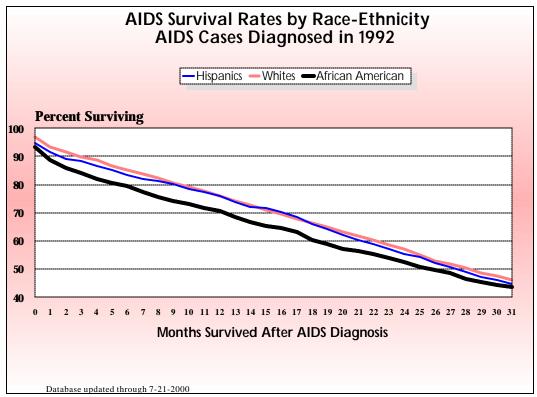


Figure 26: Survival After and AIDS Diagnosis in 1992

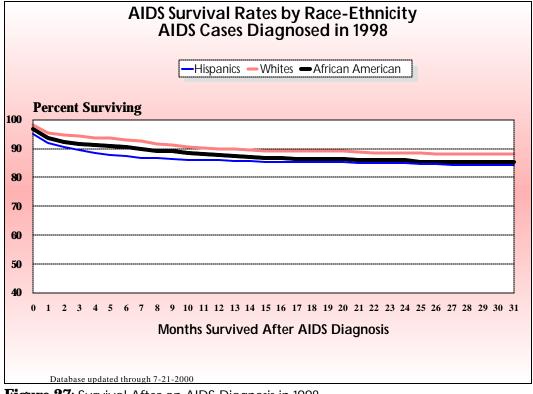


Figure 27: Survival After an AIDS Diagnosis in 1998

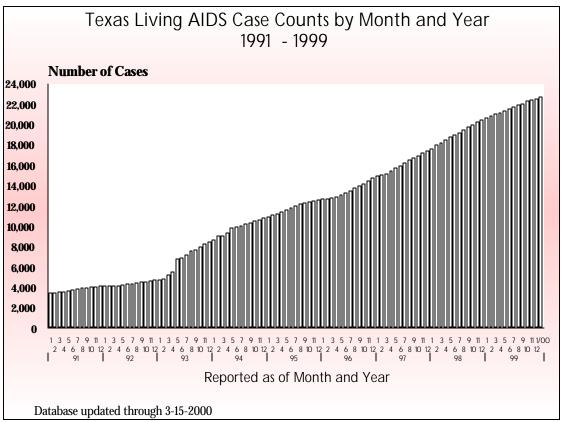


Figure 28: The Rise in the Number of Texas Living AIDS Cases: AIDS Prevalence

Appendix 3: Public Health Regions

Table 3.1

Numbers and Proportions of Publicly Funded Tests Conducted Anonymously (A) and Confidentially (C) in Texas, 1994, 1998, and 1999

		199	94			19'	98			19	99	
Region	Anony	ymous	Confic	dential	Anony	ymous	Confic	dential	Anon	ymous	Confic	lential
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
1	3,014	26.0%	8,596	74.0%	425	4.1%	9,898	95.9%	531	6.5%	7,670	93.5%
2	1,028	25.3%	3,039	74.7%	440	17.3%	2,098	82.7%	86	4.9%	1,675	95.1%
3	8,457	31.3%	18,602	68.7%	3,770	19.2%	15,911	80.8%	4,008	19.1%	16,951	80.9%
4	670	10.6%	5,654	89.4%	185	3.3%	5,417	96.7%	272	5.3%	4,829	94.7%
5	2,234	24.1%	7,030	75.9%	739	10.2%	6,528	89.8%	586	10.8%	4,839	89.2%
6	8,660	18.1%	3,928	81.9%	7,201	18.1%	32,483	81.9%	7,200	17.4%	34,088	82.6%
7	9,810	33.4%	1,955	66.6%	4,572	26.0%	13,021	74.0%	3,568	20.6%	13,774	79.4%
8	7,260	54.8%	5,985	45.2%	3,490	43.8%	4,474	56.2%	2,881	38.7%	4,569	61.3%
9	526	14.0%	3,237	86.0%	242	5.9%	3,870	94.1%	334	8.5%	3,586	91.5%
10	467	4.6%	9,679	95.4%	291	5.8%	4,724	94.2%	288	7.4%	3,618	92.6%
11	2,191	23.1%	7,283	76.9%	929	9.4%	8,909	90.6%	674	6.5%	9,679	93.5%

Public Health Region 1 Appendix

Table 3.2

Pagin 1 Adults and Adalescents							
Region 1 Adults and Adolescents							
1999 HIV Cases, AIDS Cases and Estimated Population by County							
	Total			Total	HIV &		
	Age 13+		HIV	HIV &	AIDS		
County	Population	AIDS	(Not AIDS)	AIDS	Rate*		
Armstrong	1,691	0	0	0	0.0		
Bailey	5,938	0	0	0	0.0		
Briscoe	1,617	0	0	0	0.0		
Carson	5,331	0	0	0	0.0		
Castro	7,383	0	0	0	0.0		
Childress	5,889	0	0	0	0.0		
Cochran	3,784	0	0	0	0.0		
Collingsworth	2,810	0	0	0	0.0		
Crosby	5,957	0		0	0.0		
Dallam	4,352	3		3	68.9		
Deaf Smith	15,255	0		0	0.0		
Dickens	2,051	0		0	0.0		
Donley	2,959	0		0	0.0		
Floyd	6,860	0	0	0	0.0		
Garza	4,276	1	0	1	23.4		
Gray	18,687	0	0	0	0.0		
Hale	26,936	1	1	2	7.4		
Hall	3,049	0	0	0	0.0		
Hansford	4,735	0		0	0.0		
Hartley	4,263	0		0	0.0		
Hemphill	2,966	0	0	0	0.0		
Hockley	19,454	0		0	0.0		
Hutchinson	20,237	2	0	2	9.9		
King	322	0	0	0	0.0		
Lamb	11,624	0	0	0	0.0		
Lipscomb	2,548	0	0	0	0.0		
Lubbock	179,824	39	38	77	42.8		
Lynn	5,446	0	1	1	18.4		
Moore	14,584	1	1	2	13.7		
Motley	1,236	0	0	0	0.0		
Ochiltree	7,279	0	0	0	0.0		
Oldham	1,872	0	0	0	0.0		
Parmer	8,090	0	0	0	0.0		
Potter	84,929	20	7	27	31.8		
Randall	88,913	3	2	5	5.6		
Roberts	859	0	0	0	0.0		
Sherman	2,420	0	0	0	0.0		
Swisher	7,009	0	0	0	0.0		
Terry	11,063	0	0	0	0.0		
Wheeler	4,537	0	0	0	0.0		
Yoakum	7,439	1	0	1	13.4		
Total	616,474	71	50	121	19.6		

Population Estimates Taken from Epigram on 5/30/2000: HIV/AIDS database updated as of 1-20-2000:

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 1 Appendix

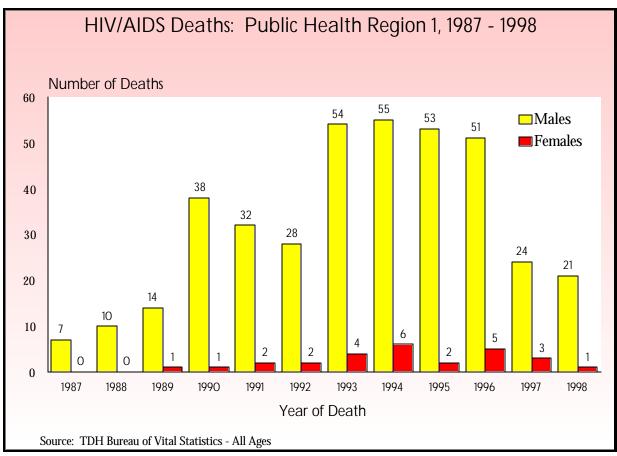


Figure 29: Public Health Region 1 Deaths

Public Health Region 1 Appendix

Table 3.3

Living HIV and AIDS Cases as of the End of 1999 Public Health Region 1 by Residence County						
County	HIV	AIDS	Total			
		AID3	Tutai			
Bailey	0	1	1			
Crosby	0	1	1			
Dallam	0	5	5			
Deaf Smith	0	5	5			
Donley	0	1	1			
Floyd	0	2	2			
Garza	0	1	1			
Gray	0	2	2			
Hale	2	7	9			
Hall	0	1	1			
Hemphill	0	1	1			
Hockley	0	3	3			
Hutchinson	0	2	2			
Lamb	0	3	3			
Lubbock	42	123	165			
Lynn	1	1	2			
Moore	1	2	3			
Ochiltree	1	2	3			
Parmer	0	2	2			
Potter	6	97	103			
Randall	2	10	12			
Terry	0	1	1			
Yoakum	0	2	2			
Region 1 Total	55	275	330			

All Ages

Database updated as of January 20, 2000

 $Residence\ County\ Refers\ to\ the\ place\ they\ were\ living\ when\ they\ were\ diagnosed\ with\ HIV\ or\ AIDS$

Public Health Region 2 Appendix

Table 3.4

l able 3.4 Region 2 Adults and Adolescents 1999 HIV, AIDS and Estimated Population by County							
		and Estima	ated Population				
	Total		HIV	Total	HIV &		
County	Age 13+ Population	AIDS	(Not AIDS)	HIV & AIDS	AIDS Rate*		
County	Fopulation	AID3	(NOT AIDS)	AID3	Nate		
Archer	6,964	0		0	0.0		
Baylor	3,456	0		0	0.0		
Brown	27,974	1	. 2	3	10.7		
Callahan	10,104	0	0	0	0.0		
Clay	8,445	0	0	0	0.0		
Coleman	7,618	1	. 0	1	13.1		
Comanche	11,015	0	0	0	0.0		
Cottle	1,807	0	0	0	0.0		
Eastland	14,739	2	1	3	20.4		
Fisher	3,873	0	1	1	25.8		
Foard	1,439	0	0	0	0.0		
Hardeman	4,133	1	. 1	2	48.4		
Haskell	5,436	0	0	0	0.0		
Jack	5,629	2	0	2	35.5		
Jones	16,023	0	0	0	0.0		
Kent	852	0	0	0	0.0		
Knox	3,860	0	0	0	0.0		
Mitchell	7,667	0	0	0	0.0		
Montague	13,367	1	1	2	15.0		
Nolan	13,650	1	0	1	7.3		
Runnels	9,276	0	0	0	0.0		
Scurry	15,840	0	0	0	0.0		
Shackelford	2,644	0	0	0	0.0		
Stephens	7,506	0	0	0	0.0		
Stonewall	1,618	0	0	0	0.0		
Taylor	99,168	8	6	14	14.1		
Throckmort	1,532	0	0	0	0.0		
Wichita	103,462	13	15	28	27.1		
Wilbarger	12,601	2	3	5	39.7		
Young	13,949	0	0	0	0.0		
Total	435,647	32	30	62	14.2		

 $Population \ Estimates \ Taken \ from \ Epigram \ on \ 5/30/2000. \ \ HIV/AIDS \ database \ updated \ as \ of \ 1-20-2000.$

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 2 Appendix

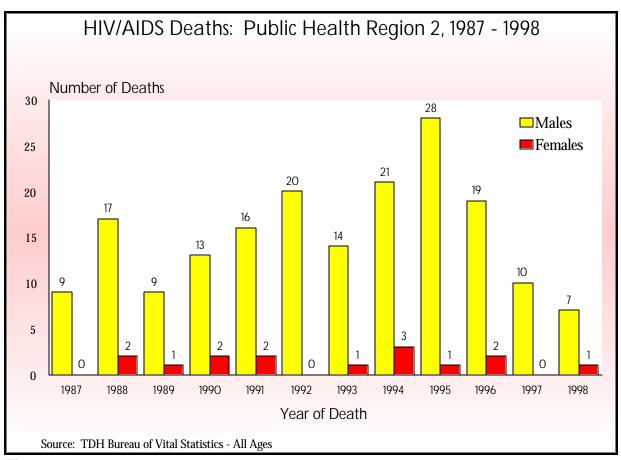


Figure 30: Public Health Region 2 Deaths

Public Health Region 2 Appendix

Table 3.5

Living HIV and AIDS Cases as of the End of 1999 Public Health Region 2 by Residence County							
County	nty HIV AIDS Total						
Archer	0	1	1				
Brown	2	9	11				
Callahan	0	3	3				
Clay	0	1	1				
Coleman	0	4	4				
Comanche	1	3	4				
Eastland	1	5	6				
Fisher	1	2	3				
Hardeman	1	6	7				
Haskell	0	1	1				
Jack	0	4	4				
Jones	0	4	4				
Mitchell	0	2	2				
Montague	1	3	4				
Nolan	0	5	5				
Runnels	0	1	1				
Scurry	0	3	3				
Taylor	7	61	68				
Wichita	15	91	106				
Wilbarger	3	13	16				
Young	0	4	4				
Region 2 Total	32	226	258				

All Ages

Database updated as of January 20, 2000

 $Residence\ County\ refers\ to\ the\ place\ they\ were\ living\ when\ they\ were\ diagnosed\ with\ HIV\ or\ AIDS$

Public Health Region 3 Appendix

Table 3.6

Region 3 Adults and Adolescents 1999 HIV, AIDS and Estimated Population by County							
County	Total Age 13+ Population	AIDS	HIV (Not AIDS)	Total HIV & AIDS	HIV & AIDS Rate*		
	•		,				
Collin	334,850	18	10	28	8.4		
Cooke	26,310	2	0	2	7.6		
Dallas	1,727,471	536	550	1,086	62.9		
Denton	323,169	20	18	38	11.8		
Ellis	95,390	7	5	12	12.6		
Erath	25,454	1	0	1	3.9		
Fannin	21,709	1	0	1	4.6		
Grayson	79,872	9	10	19	23.8		
Hood	35,234	3	2	5	14.2		
Hunt	59,199	4	2	6	10.1		
Johnson	110,933	8	3	11	9.9		
Kaufman	57,774	8	6	14	24.2		
Navarro	35,669	3	0	3	8.4		
Palo Pinto	21,891	0	1	1	4.6		
Parker	75,581	0	2	2	2.6		
Rockwall	32,489	2	1	3	9.2		
Somervell	5,209	1	0	1	19.2		
Tarrant	1,213,174	133	126	259	21.3		
Wise	34,782	4	4	8	23.0		
Total	4,316,160	760	740	1,500	34.8		

Population Estimates Taken from Epigram on 5/30/2000. HIV/AIDS database updated as of 1-20-2000.

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 3 Appendix

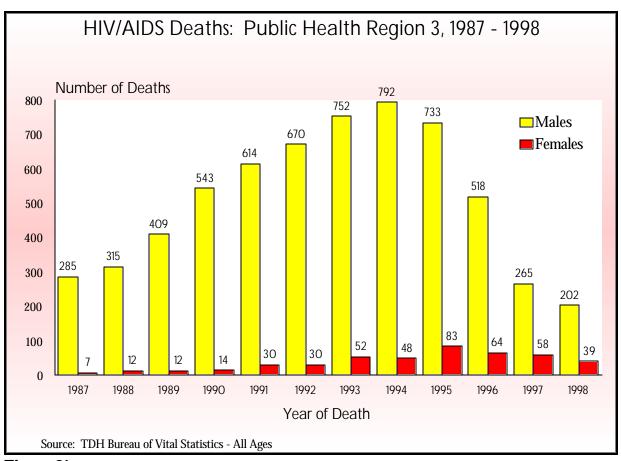


Figure 31: Public Health Region 3 - Deaths

Public Health Region 3 Appendix

Table 3.7

Living HIV and AIDS Cases as of the End of 1999							
o o	h Region 3 b						
		•					
County	HIV	AIDS	Total				
Collin	13	121	134				
Cooke	0	10	10				
Dallas	578	4,781	5,359				
Denton	20	164	184				
Ellis	9	40	49				
Erath	0	3	3				
Fannin	0	6	6				
Grayson	11	51	62				
Hood	2	14	16				
Hunt	2	29	31				
Johnson	4	39	43				
Kaufman	6	36	42				
Navarro	0	23	23				
Palo Pinto	1	10	11				
Parker	4	26	30				
Rockwall	1	12	13				
Somervell	0	3	3				
Tarrant	140	1,335	1,475				
Wise	4	12	16				
Region 3 Total	795	6,715	7,510				

All Ages

Database updated as of January 20, 2000

Residence County refers to the place they were living when they were diagnosed with HIV or AIDS

Public Health Region 4 Appendix

Table 3.8

Region 4 Adults and Adolescents								
	1999 HIV, AIDS and Estimated Population by County							
	Total			Total	HIV &			
	Age 13+		HIV	HIV &	AIDS			
County	Population	AIDS	(Not AIDS)	AIDS	Rate*			
Anderson	44,168	7	9	16	36.2			
Bowie	68,770	8	12	20	29.1			
Camp	8,774	2	0	2	22.8			
Cass	24,499	2	2	4	16.3			
Cherokee	35,844	6	3	9	25.1			
Delta	4,034	0	0	0	0.0			
Franklin	6,735	0	0	0	0.0			
Gregg	86,971	18	12	30	34.5			
Harrison	51,990	3	4	7	13.5			
Henderson	63,627	9	5	14	22.0			
Hopkins	24,448	6	3	9	36.8			
Lamar	35,305	6	10	16	45.3			
Marion	8,744	1	1	2	22.9			
Morris	10,601	0	0	0	0.0			
Panola	19,671	7	1	8	40.7			
Rains	6,768	1	0	1	14.8			
Red River	11,524	1	1	2	17.4			
Rusk	37,718	2	5	7	18.6			
Smith	139,025	18	18	36	25.9			
Titus	20,087	4	5	9	44.8			
Upshur	27,602	1	6	7	25.4			
Van Zandt	35,974	3	1	4	11.1			
Wood	28,038	4	0	4	14.3			
Total	800,917	109	98	207	25.8			

 $Population \ Estimates \ Taken \ from \ Epigram \ on \ 5/30/2000. \ \ HIV/AIDS \ database \ updated \ as \ of \ 1-20-2000.$

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 4 Appendix

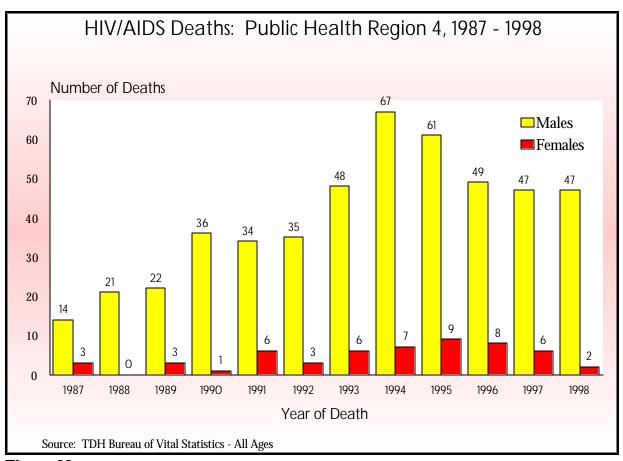


Figure 32: Public Health Region 4 - Deaths

Public Health Region 4 Appendix

Table 3.9

Living HIV and AIDS Cases as of the End of 1999						
Public Health Region 4 by Residence County						
County	HIV	HIV AIDS Total				
Anderson	10	21	31			
Bowie	10	50	62			
	0	5	5			
Camp	_	_	-			
Cass	2	12	14			
Cherokee	3	23	26			
Gregg	12	92	104			
Harrison	5	27	32			
Henderson	5	25	30			
Hopkins	3	9	12			
Lamar	10	11	21			
Marion	1	3	4			
Morris	0	3	3			
Panola	2	10	12			
Rains	0	1	1			
Red River	1	4	5			
Rusk	6	13	19			
Smith	18	98	116			
Titus	5	11	16			
Upshur	5	16	21			
Van Zandt	1	8	9			
Wood	0	15	15			
Region 4 Total	101	457	558			

All Ages

Database updated as of January 20, 2000

 $Residence\ County\ refers\ to\ the\ place\ they\ were\ living\ when\ they\ were\ diagnosed\ with\ HIV\ or\ AIDS$

Public Health Region 5 Appendix

Table 3.10

Region 5 Adults and Adolescents 1999 HIV, AIDS and Estimated Population by County					
	Total Age 13+		HIV	Total HIV &	HIV & AIDS
County	Population	AIDS	(Not AIDS)	AIDS	Rate*
Angelina Hardin	59,372 34,830	11 1	9	20 1	33.7 2.9
Houston	18,912 25,991	7	1	8	42.3 3.8
Jasper Jefferson	25,991 191,376	20	31	51	26.6
Nacogdoch Newton	46,834	7	5 0	12 0	25.6
Orange	11,970 66,607	0 5	3	8	0.0 12.0
Polk	32,308	5	4	9	27.9
Sabine San	8,693 6,641	1 1	0	1 1	11.5 15.1
San Jacinto	17,588	3	0	3	17.1
Shelby	17,756	5	0	5	28.2
Trinity Tyler	10,767 15,709	3 0	2	5 0	$\begin{array}{c} 46.4 \\ 0.0 \end{array}$
Total	565,354	70	55	125	22.1

Population Estimates Taken from Epigram on 5/30/2000: HIV/AIDS database updated as of 1-20-2000:

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 5 Appendix

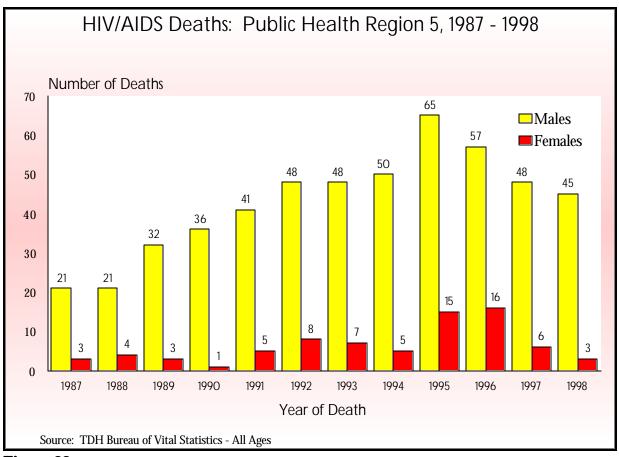


Figure 33: Public Health Region 5 - Deaths

Public Health Region 5 Appendix

Table 3.11

Living HIV and AIDS Cases as of the End of 1999							
Public Health Region 5 by Residence County							
County	County HIV AIDS Total						
Angelina	9	27	36				
Hardin	0	10	10				
Houston	2	12	14				
Jasper	0	6	6				
Jefferson	34	256	290				
Nacogdoches	6	26	32				
Newton	0	3	3				
Orange	3	30	33				
Polk	5	17	22				
Sabine	0	2	2				
San Augustine	1	3	4				
San Jacinto	1	8	9				
Shelby	0	18	18				
Trinity	2	10	12				
Tyler	0	5	5				
Region 5 Total	63	433	496				

All Ages

Database updated as of January 20, 2000

 $Residence\ County\ refers\ to\ the\ place\ they\ were\ living\ when\ they\ were\ diagnosed\ with\ HIV\ or\ AIDS$

Public Health Region 6 Appendix

Table 3.12

	Degler /	A dulta ara		un to	
Region 6 Adults and Adolescents					
1999 HIV, AIDS and Estimated Population by County					
	Total			Total	HIV &
			1.1157		
0	Age 13+	AIDC	HIV	HIV &	AIDS
County	Population	AIDS	(Not	AIDS	Rate*
			AIDS)		
Austin	17,188	1	0	1	5.8
Brazoria	177,873	8	2	10	5.6
	,	_			
Chambers	17,196	0	0	0	0.0
Colorado	14,984	0	3	3	20.0
Fort Bend	258,822	13	21	34	13.1
Galveston	188,204	20	11	31	16.5
Harris	2,566,910	678	899	1,577	61.4
Liberty	49,373	4	6	10	20.3
Matagorda	30,260	3	3	6	19.8
Montgome	191,190	11	4	15	7.8
Walker	44,966	0	3	3	6.7
Waller	21,424	1	0	1	4.7
Wharton	32,927	5	3	8	24.3
Total	3,611,317	744	955	1,699	47.0

Population Estimates Taken from Epigram on 5/30/2000. HIV/AIDS database updated as of 1-20-2000.

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 6 Appendix

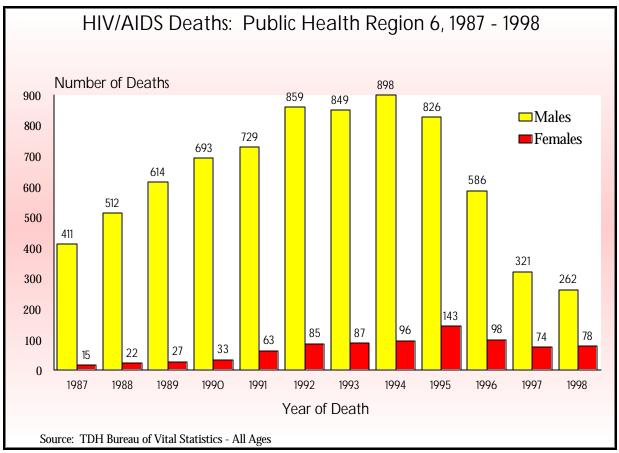


Figure 34: Public Health Region 6 - Deaths

Public Health Region 6 Appendix

Table 3.13

Living HIV and AIDS Cases as of the End of 1999						
Public Health Region 6 by Residence County						
County	HIV AIDS Total					
Austin	0	7	7			
Brazoria	4	86	90			
Chambers	0	3	3			
Colorado	3	1	4			
Fort Bend	25	25 165 190				
Galveston	14	260	274			
Harris	1,046	7,387	8,433			
Liberty	7	35	42			
Matagorda	4	9	13			
Montgomery	5	103	108			
Walker	3	18	21			
Waller	1	20	21			
Wharton	2	19	21			
Region 6 Total	1,114	8,113	9,227			

All Ages

Database updated as of January 20, 2000

 $Residence\ County\ refers\ to\ the\ place\ they\ were\ living\ when\ they\ were\ diagnosed\ with\ HIV\ or\ AIDS$

Public Health Region 7 Appendix

Table 3.14

Region 7 Adults and Adolescents					
1999 HIV, AIDS and Estimated Population by County					
	Total			Total	HIV &
	Age 13+		HIV	HIV &	AIDS
County	Population	AIDS	(Not AIDS)	AIDS	Rate*
Bastrop	44,564	4	3	7	15.7
Bell	163,421	20	11	31	19.0
Blanco	6,218	0	0	0	0.0
Bosque	13,536	1	1	2	14.8
Brazos	99,096	17	12	29	29.3
Burleson	12,600	4	1	5	39.7
Burnet	23,739	2	0	2	8.4
Caldwell	26,154	0	2	2	7.6
Coryell	59,973	5	3	8	13.3
Falls	15,454	1	3	4	25.9
Fayette	17,322	3	1	4	23.1
Freestone	14,386	1	0	1	7.0
Grimes	19,025	1	1	2	10.5
Hamilton	6,185	0	0	0	0.0
Hays	73,251	10	1	11	15.0
Hill	23,807	1	0	1	4.2
Lampasas	11,765	1	0	1	8.5
Lee	12,304	2	0	2	16.3
Leon	13,276	0	0	0	0.0
Limestone	17,791	1	1	2	11.2
Llano	11,045	0	0	0	0.0
McLennan	155,216	13	24	37	23.8
Madison	10,318	0	0	0	0.0
Milam	19,012	6	2	8	42.1
Mills	3,719	0	0	0	0.0
Robertson	13,775	3	0	3	21.8
San Saba	4,540	0	0	0	0.0
Travis	515,937	245	114	359	69.6
Washington	24,593	2	1	3	12.2
Williamson	172,258	12	4	16	9.3
Total	1,604,280	355	185	540	33.7

Population Estimates Taken from Epigram on 5/30/2000: HIV/AIDS database updated as of 1-20-2000:

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 7 Appendix

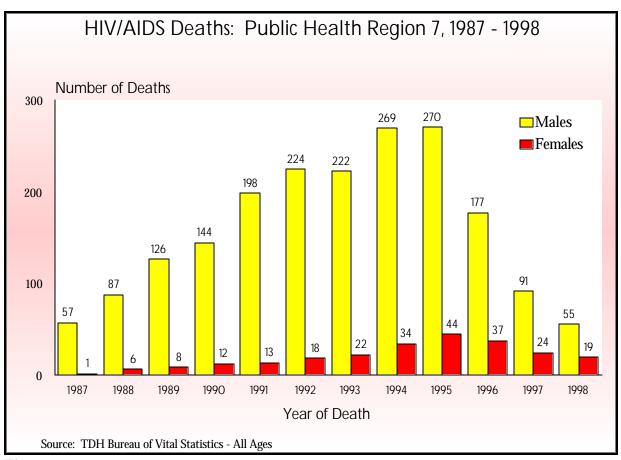


Figure 35: Public Health Region 7 - Deaths

Public Health Region 7 Appendix

Table 3.15

Living HIV and AIDS Cases as of the End of 1999 Public Health Region 7 by Residence County						
County	HIV AIDS Total					
Bastrop	4	36	40			
Bell	10	113	123			
Blanco	0	3	3			
Bosque	1	6	7			
Brazos	13	57	70			
Burleson	2	9	11			
Burnet	0	11	11			
Caldwell	2	12	14			
Coryell	3	14	17			
Falls	3	3	6			
Fayette	1	8	9			
Freestone	0	4	4			
Grimes	1	5	6			
Hamilton	1	4	5			
Hays	1	43	44			
Hill	0	9	9			
Lampasas	0	4	4			
Lee	0	3	3			
Leon	0	5	5			
Limestone	1	7	8			
Llano	0	2	2			
Mclennan	22	121	143			
Madison	0	3	3			
Milam	2	12	14			
Robertson	0	9	9			
Travis	129	1,482	1,611			
Washington	1	6	7			
Williamson 4 60 64						
Region 7 Total 201 2,051 2,252						

All Ages

Database updated as of January 20, 2000

 $Residence\ County\ refers\ to\ the\ place\ they\ were\ living\ when\ they\ were\ diagnosed\ with\ HIV\ or\ AIDS$

Public Health Region 8 Appendix

Table 3.16

Region 8 Adults and Adolescents					
1999 HIV, AIDS and Estimated Population by County					
Total Total HIV &					
	Age 13+		HIV	HIV &	AIDS
County	Population	AIDS	(Not AIDS)	AIDS	Rate*
			•		
Atascosa	29,355	0	0	0	0.0
Bandera	11,965	0	0	0	0.0
Bexar	1,069,167	204	153	357	33.4
Calhoun	16,132	1	0	1	6.2
Comal	62,562	3	4	7	11.2
DeWitt	16,992	0	0	0	0.0
Dimmit	8,693	2	0	2	23.0
Edwards	1,976	1	0	1	50.6
Frio	12,813	0	0	0	0.0
Gillespie	17,265	0	0	0	0.0
Goliad	5,403	0	0	0	0.0
Gonzales	14,537	0	2	2	13.8
Guadalupe	68,702	1	4	5	7.3
Jackson	10,953	1	0	1	9.1
Karnes	13,082	0	1	1	7.6
Kendall	15,767	2	1	3	19.0
Kerr	35,301	1	2	3	8.5
Kinney	2,785	0	0	0	0.0
La Salle	5,078	2	0	2	39.4
Lavaca	14,984	0	0	0	0.0
Maverick	32,302	3	3	6	18.6
Medina	27,973	3	0	3	10.7
Real	2,068	0	0	0	0.0
Uvalde	19,843	1	0	1	5.0
Val Verde	33,168	2	2	4	12.1
Victoria	64,351	1	2	3	4.7
Wilson	24,104	2	0	2	8.3
Zavala	10,423	1	0	1	9.6
Total	1,647,744	231	174	405	24.6

Population Estimates Taken from Epigram on 5/30/2000: HIV/AIDS database updated as of 1-20-2000:

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 8 Appendix

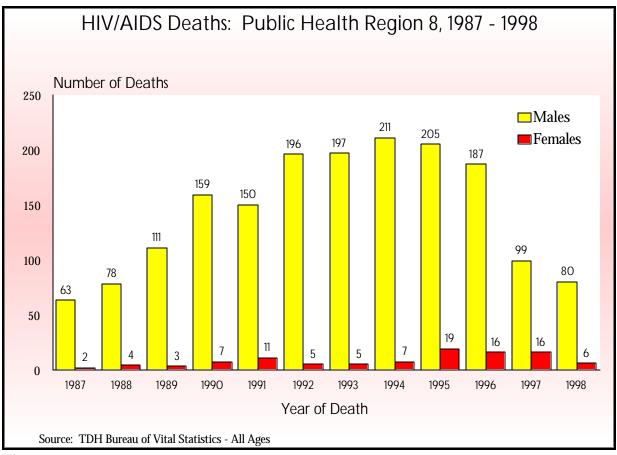


Figure 36: Public Health Region 8 - Deaths

Public Health Region 8 Appendix

Table 3.17

Living HIV and AIDS Cases as of the End of 1999				
Public Health Region 8 by Residence County				
County	HIV	AIDS	Total	
Atascosa	0	5	5	
Bandera	0	2	2	
Bexar	154	1,731	1,885	
Calhoun	0	9	9	
Comal	4	23	27	
De Witt	0	1	1	
Dimmit	0	2	2	
Edwards	0	1	1	
Frio	0	1	1	
Gonzales	2	5	7	
Guadalupe	4	14	18	
Jackson	0	1	1	
Karnes	1	1	2	
Kendall	1	6	7	
Kerr	3	19	22	
Kinney	0	1	1	
Lasalle	0	2	2	
Lavaca	0	2	2	
Maverick	3	15	18	
Medina	0	7	7	
Real	0	1	1	
Uvalde	0	4	4	
Val Verde	2	4	6	
Victoria	5	29	34	
Wilson	0	8	8	
Zavala	0	2	2	
Region 8 Total	179	1,896	2,075	

All Ages

Database updated as of January 20, 2000

Residence \hat{C} ounty refers to the place they were living when they were diagnosed with HIV or AIDS

Public Health Region 9 Appendix

Table 3.18

Pagian O. Adulta and Adalescents					
Region 9 Adults and Adolescents					
1999 HIV, AIDS and Estimated Population by County					
	Total			Total	HIV &
	Age 13+		HIV	HIV &	AIDS
County	Population	AIDS	(Not AIDS)	AIDS	Rate*
Andrews	12,060	1	0	1	8.3
Borden	12,000 699	0	0	0	0.0
Coke	2,938	0	0	0	0.0
Concho	2,938 2,791	1	0	1	35.8
Crane	2,791 4,087	0	0	0	0.0
Crockett	3,485	0	0	0	0.0
Dawson	12,765	0	0	0	0.0
Ector		7	5	12	12.0
Gaines	99,853 11,414	0	0	0	0.0
Glasscock	11,414	0	0	0	0.0
	,				
Howard	25,870	2 0	2	4 0	15.5
Irion Kimble	1,409	0	0	0	0.0
	3,442	0	0	0	0.0
Loving	103				0.0
McCulloch Mortin	7,237	1 0	0	1 0	13.8
Martin	4,323	0	0	0	0.0
Mason	2,757		0		0.0
Menard	1,915	0	0	0	0.0
Midland	100,775	10	6	16	15.9
Pecos	14,177	2	0	2	14.1
Reagan	4,018	_	0	_	0.0
Reeves	13,661	0	0	0	0.0
Schleicher	2,575	0	0	0	0.0
Sterling	1,241	0	0	0	0.0
Sutton	3,572	0	0	0	0.0
Terrell Tom Green	1,268	0	0	0 6	0.0
	88,805	6 0	0	0	6.8
Upton Ward	3,811				0.0
	10,905	$0 \\ 2$	1	1 3	9.2
Winkler	7,125		1	3 47	42.1
Total	450,354	32	15	47	10.4

Population Estimates Taken from Epigram on 5/30/2000: HIV/AIDS database updated as of 1-20-2000.

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 9 Appendix

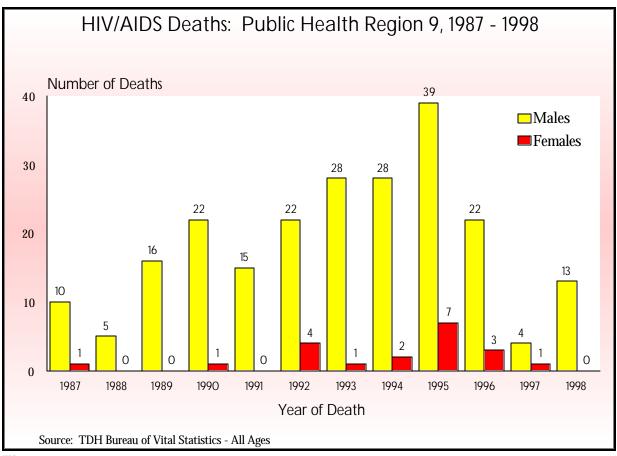


Figure 37: Public health Region 9 - Deaths

Public Health Region 9 Appendix

Table 3.19

Living HIV and AIDS Cases as of the End of 1999				
Public Health Region 9 by Residence County				
County	HIV	AIDS	Total	
Andrews	0	2	2	
Concho	0	1	1	
Crockett	0	1	1	
Dawson	0	2	2	
Ector	5	55	60	
Howard	2	11	13	
Kimble	0	1	1	
Mcculloch	0	3	3	
Martin	0	1	1	
Midland	5	53	58	
Pecos	0	4	4	
Reeves	0	3	3	
Schleicher	0	2	2	
Sutton	0	1	1	
Tom Green	1	40	41	
Ward	2	4	6	
Winkler	1	3	4	
Region 9 Total	16	187	203	

All Ages

Database updated as of January 20, 2000

Residence County refers to residence when diagnosed with HIV or AIDS

Public Health Region 10 Appendix

Table 3.20

Region 10 Adults and Adolescents 1999 HIV, AIDS and Estimated Population by County					
Total Total HIV & AIDS Age 13+ HIV HIV & AIDS County Population AIDS (Not AIDS) AIDS Rate*					
Brewster	9,025	0	0	0	0.0
Culberson El Paso	3,168 571,390	0 87	0 55	$0\\142$	$\begin{array}{c} 0.0 \\ 24.9 \end{array}$
Hudspeth Jeff Davis	2,640 1,832	0	0 0	0 0	0.0 0.0
Presidio Total	6,563 594,618	0 87	0 55	0 142	0.0 23.9

Population Estimates Taken from Epigram on 5/30/2000: HIV/AIDS database updated as of 1-20-2000:

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 10 Appendix

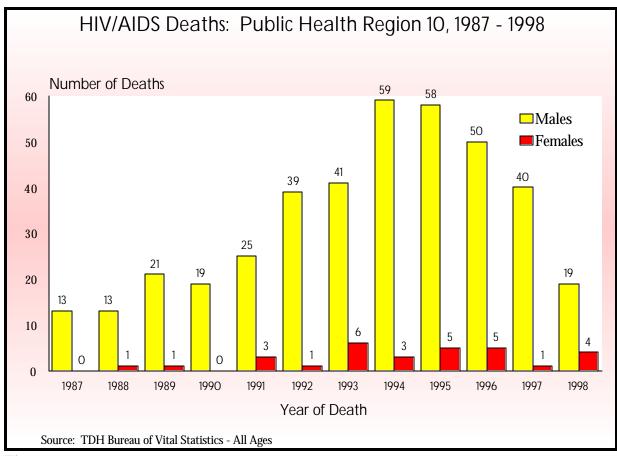


Figure 38: Public Health Region 10 - Deaths

Public Health Region 10 Appendix

Table 3.21

Living HIV and AIDS Cases as of the End of 1999						
Public Health Region 10 by Residence County						
County HIV AIDS Total						
Culberson 0 1 1 El Paso 59 514 573						
Region 10 Total 59 515 574						

All Ages

Database updated as of January 20, 2000

Residence County refers to the place they were living when they were diagnosed with HIV or AIDS

Public Health Region 11 Appendix

Table 3.22

Region 11 Adults and Adolescents 1999 HIV, AIDS and Estimated Population by County					
	Total Age 13+	ALDO	HIV	Total HIV &	HIV & AIDS
County	Population	AIDS	(Not AIDS)	AIDS	Rate*
Aransas	16,468	2	1	3	18.2
Bee	23,430	7	0	7	29.9
Brooks	6,905	1	1	2	29.0
Cameron	246,004	25	16	41	16.7
Duval	11,561	0	0	0	0.0
Hidalgo	393,127	30	25	55	14.0
Jim Hogg	4,966	0	0	0	0.0
Jim Wells	31,144	1	1	2	6.4
Kenedy	420	0	0	0	0.0
Kleberg	24,952	1	1	2	8.0
Live Oak	8,261	0	0	0	0.0
McMullen	716	0	0	0	0.0
Nueces	248,908	40	28	68	27.3
Refugio	6,675	0	1	1	15.0
San Patricio	53,392	6	5	11	20.6
Starr	44,230	2	1	3	6.8
Webb	131,331	11	15	26	19.8
Willacy	15,120	2	1	3	19.8
Zapata	9,781	0	0	0	0.0
Total	1,277,391	128	96	224	17.5

Population Estimates Taken from Epigram on 5/30/2000. HIV/AIDS database updated as of 1-20-2000.

^{*}Rates per 100,000 Estimated population 1999 = Year of Report

Public Health Region 11 Appendix

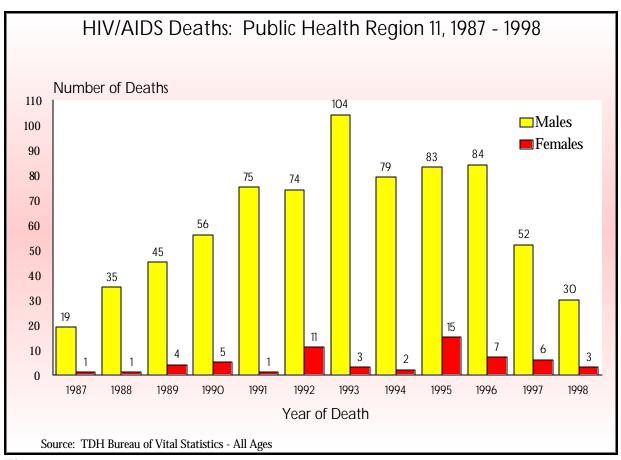


Figure 39: Public Health Region 11 - Deaths

Public Health Region 11 Appendix

Table 3.23

Living HIV and AIDS Cases as of the End of 1999							
Public Health Region 11 by Residence County							
County	HIV AIDS Total						
Oddity	1110	71100	rotar				
Aransas	1	13	14				
Bee	0	11	11				
Brooks	1	3	4				
Cameron	17	166	183				
Duval	0	3	3				
Hidalgo	27	183	210				
Jim Wells	1	5	6				
Kleberg	1	11	12				
Live Oak	0	3	3				
Nueces	33	238	271				
Refugio	1	1	2				
San Patricio	6	21	27				
Starr	1	10	11				
Webb	16	96	112				
Willacy	1	6	7				
Region 11 Total	,						

All Ages

Database updated as of January 20, 2000 Residence County refers to the place they were living when they were diagnosed with HIV or AIDS

Appendix 4: Surveillance Practices

The concept of public health surveillance has changed over time and is still confused with other uses of the term *surveillance*. The current idea of surveillance as the monitoring of disease occurrence in populations has been strongly promoted by the Centers for Disease Control and Prevention (CDC) in Atlanta. Before that, surveillance had meant the close observation of persons who had been exposed to a communicable disease in order to detect early symptoms and to institute prompt isolation and control measures. To distinguish between these two surveillance activities, the term *public health surveillance* is used to describe monitoring health events in populations, and the term *medical surveillance* is used to describe monitoring potentially exposed individuals to detect early symptoms.

Why is Public Health Surveillance Important?

Public Health Surveillance data have many uses. The goal of surveillance is not merely to collect data for analysis, but to guide public health policy and action. Surveillance has been defined as "information for action". Some of the uses for surveillance data include:

- i Providing information and referrals to services to clients
- i Priority setting
- Planning, implementing, and evaluating
 - ! disease investigation
 - ! disease control
 - ! disease prevention

The ultimate purpose for conducting public health surveillance is to learn the ongoing pattern of disease occurrence and the potential for disease in a population so that there can be effective measures for investigating, controlling and preventing disease in that population. Surveillance data are also used in the following ways:

- i to monitor health events for changes in disease occurrence and distribution
- i to monitor long-term trends and patterns of disease
- i to detect changes in health care practices
- i to target strategies and anticipate needs
- i to search for outbreak sources and implement outbreak control measures
- i to plan for future resource needs
- i to evaluate prevention, control and/or treatment methods
- i to generate new and needed public health research

The collection of surveillance information also provides an opportunity for public health workers to intervene in the cycle of infection. In Texas, surveillance specialists are the link between the

physicians who report disease and the Disease Intervention Specialists (DIS); in many counties, surveillance staff *are* DIS. DIS are specially trained health professionals who offer infected individuals an opportunity to have their sex and/or needle sharing partners anonymously and discreetly notified that they have been exposed to HIV. At the present time, this service is offered to all patients who are diagnosed with HIV and certain STDs in publicly funded settings. It is also offered, after consultation with providers, to patients diagnosed with certain STDs in private clinical settings. due to the current method of reporting HIV, DIS services are not consistently available to individuals diagnosed with HIV in private settings.

Where Does Public Health Surveillance Information Come From?

There are many sources of data available that can be used for public health surveillance. Some of the key sources include:

- i Mortality reports information obtained from vital statistics, including birth and death certificates;
- i Morbidity reports reports of disease are called "morbidity" and these reports can be obtained from positive laboratory tests, hospital discharge information, disease reports from other states, and disease reports sent in from private providers;
- i Surveys special surveys, such as the Behavioral Risk Factor Surveillance System, can be used to gather information that can be used in public health surveillance; and,
- i Other disease indicators monitoring information from other health areas can provide information crucial to a surveillance system. Animal populations are often important in monitoring the occurrence of diseases such as rabies, encephalitis or plague. Environmental information and drug utilization information can also be used in a public health surveillance system.

Traditionally, a surveillance system may be classified as passive or active. A passive surveillance system can be described as one in which the health jurisdiction receives disease reports from physicians or other individuals or institutions as mandated by law. An active surveillance system is established when the health department regularly contacts reporting sources (once a week, monthly, etc.) to elicit reports, including reports of "no disease". An active surveillance system is likely to provide more complete reporting but is much more labor intensive and is more costly to operate than a passive system.

In many situations, additional cases of disease that were previously unknown can be located through an "alternate records" data search. Surveillance professionals will review other sources of case information and compare the information they've found there with the existing known cases. For example, case-finding be done by obtaining a database from the Tuberculosis Program and reviewing it to determine if there are unknown AIDS cases listed on that database. In Texas, the

alternate records matching is a source of about 10% of all reported AIDS cases.

How is a Surveillance System Established and Altered?

Each state government establishes what health events must be reported by health care providers in that state. Some states require as few as 35 conditions or diseases to be reported; others require as many as 130 conditions or diseases. In general, a state includes a disease on its list if the disease (1) causes serious morbidity (illness) or death, (2) has the potential to affect additional people beyond the reported case, and (3) can be controlled or prevented with proper intervention. Most states also require that an outbreak of any condition be reported.

In Texas, the rules for how communicable diseases are reported to the public health surveillance system are contained in the Texas Administrative Code, Chapter 97. Disease reporting rules specify:

- i the case definitions for reportable diseases;
- i who is responsible for reporting a suspected or confirmed case of disease;
- i what information about the case is to be reported; and,
- i to whom this information should be reported, including how and when the information should be reported.

Changes to reporting rules must be proposed and approved by the Board of Health. Rule changes are proposed by a section of the Texas Department of Health and presented to the Board for initial consideration. Then, the Board will determine an appropriate length of time for public comment on the proposed changes to the reporting rules. During the public comment period, the segment of the Texas Department of Health making the rule change recommendations will compile and respond to any public comments received. At the close of the public comment period, the Board will vote whether or not to adopt the recommended rule changes.

Who is Responsible for Sending in Disease Report Information?

Any person or organization having knowledge that a person has been diagnosed with a reportable illness should be encouraged to report all information known to them concerning the disease or condition. Traditionally, this duty falls to the major "reporting sources"

- i Hospitals and hospital-based physicians
- i Physicians in non-hospital practice
- i Dentists, nurses and other health professionals
- i Medical examiners
- i Health clinics that provide clinical diagnoses
- i Laboratories
- i Administrators of hospitals, clinics, nursing homes, schools and nurseries

In Texas, the Texas Administrative Code, Chapter 97, mandates the individuals who are required to report communicable disease information to the local surveillance authority. This code also defines that failure to report this information is a Class B misdemeanor in Texas.

How Does a Public Health Surveillance System Work?

Reporting of communicable diseases occurs in three major steps: initial morbidity reporting ("notification"); submission of a completed case report form; and, updates to existing known case information. Most initial morbidity reports ask for the patient's name, age, sex, race/ethnicity, address, date of onset or test, test result, the name and locating information on the reporting source, and the date of report. Case report forms may request more detailed information. Frequently, one or all of the three types of surveillance information submissions occur simultaneously, depending on the disease being reported. In general, an acute, limited disease will combine the initial morbidity reporting and completed case report information in a single submission and may not have any information updates at all. The best example of this is gonorrhea. The initial morbidity report (if complete) contains all data needed to constitute a "complete case report" - including treatment information. No updates to this case report would be needed, as another diagnosis date would indicate a probable reinfection and be counted again as morbidity.

In reporting an AIDS case, the local surveillance authority will generally receive an initial morbidity report that contains the minimum information needed to consider the report as a true report of disease ("morbidity"). Usually, these initial reports need follow-up by surveillance personnel or public health field staff in order to complete a full case report form. Case report forms will often request more detailed information than is required in an initial morbidity report - in the case of an AIDS report, such information includes the existence of opportunistic infections, documentation of referrals to services, risk behavior information, etc.

In Texas, individuals or institutions that are reporting morbidity are required to submit the initial

morbidity report information ("notification") to their local surveillance authority - in some cases, that will be a local health department and in others it may be a regional office or the TDH Central office. Laboratories and institutions located outside of Texas and other states' health departments will submit the initial information to the TDH Central Office surveillance staff.

If the initial morbidity report is received by a local surveillance authority, it will be reviewed to determine that all required data elements are present. If there are missing data elements, the surveillance staff or public health field staff will contact the initial morbidity report submitter to obtain the needed information. At this time, the information needed to complete the full case report form will also be requested (if applicable). Once the case report form is complete, the information will be forwarded to the Bureau surveillance staff. This submission is now accomplished on a monthly basis through the use of paper reports mailed in a confidential manner and through the use of encrypted, pass-word protected computer diskettes.

If the initial morbidity report is received at the Bureau surveillance level, the information will be assigned to a local surveillance jurisdiction for follow-up (i.e., an out-of-state laboratory reports a positive gonorrhea test on an El Paso resident, the information would be sent to the El Paso surveillance program). The local surveillance program would follow the process described above to complete the investigation and return the completed case report form to the Bureau surveillance program.

Once central surveillance receives a completed case report form on a reportable condition, the existing database will be reviewed to determine if the report is a "duplicate" of an already known case. If this is a unique case, it will be entered into the statewide database. Every month, the contents of the statewide database are stripped of client identifiers (name, address) and sent on to the CDC for compilation into their nation-wide database.

After the case report form has been completed and entered into the public health surveillance database, updates on the case information may be received. These updates can occur shortly after the initial case report is complete (with additional testing information, referrals, etc.) or it may be months or years after the initial case report is filed (dates of death, documentation of new opportunistic infections, etc.).

Appendix 5: HIV/AIDS Surveillance Technical Notes

Disease Descriptions

Human Immunodeficiency Virus (HIV): Human Immunodeficiency Virus (HIV) is a human retrovirus that infects and slowly depletes a subgroup of white blood cells called helper T-lymphocytes or CD4+ lymphocytes. These white blood cells are critical to maintaining an effective immune response

Acquired Immunodeficiency Syndrome (AIDS): Acquired Immunodeficiency Syndrome (AIDS) is the late-stage consequence of HIV infection and usually occurs years later. AIDS is a specific group of diseases or conditions that result from severe immunosuppression caused by infection with HIV. The late-stage presentation of HIV disease, AIDS, reflects the prolonged, severe destruction of vital immune cells that would normally generate an immune response and provide protection in the body. The decline in the number of CD4+ (or T-cell lymphocyte) cells is an indicator of HIV disease progression and results from the continuous replication of HIV at all stages of disease in the absence of effective antiretroviral therapy.

Surveillance Case Definitions

Surveillance Case: A person whose symptoms and signs match the criteria set by the health department for officially including that person in the disease case count.

Surveillance Case Definition: The rules for counting a person as having a disease or condition. TDH HIV/AIDS morbidity reporting rules adopt by reference the Centers for Disease Control and Prevention's case definitions. Readers must be aware that changes that have occurred may alter the interpretation of the information (i.e.: the change in AIDS case definition in 1993 widened the definition thus making it appear there were many more cases after 1992). Surveillance case definitions are needed in order to be sure everyone is counting the same thing using the same rules. Case definitions are not always the same rules that individual physicians may use in diagnosing a person with a disease.

HIV Case Definition: TDH uses the CDC case definition for HIV infection. Until recently there was no formal case definition for HIV: instead there were "classification systems, published by CDC.

The first can be found in *Current Trends Classification System for Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus Infections*, **MMWR**, May 23, 1986 / 35 (20); 334-9. CDC defined HIV infection (which was still called HTLV-III at the time) as follows:

DEFINITION OF HTLV-III/LAV INFECTION

The most specific diagnosis of HTLV-III/LAV infection is by direct identification of the virus in host tissues by virus isolation; however, the techniques for isolating HTLV-III/LAV currently lack sensitivity for detecting infection and are not readily available. For public health purposes, patients with repeatedly reactive screening tests for HTLV-III/LAV antibody (e.g., enzyme-linked immunosorbent assay) in whom antibody is also identified by the use of supplemental tests (e.g., Western blot, immunofluorescence assay) should be considered both infected and infective (8-10). Although HTLV-III/LAV infection is identified by isolation of the virus or, indirectly, by the presence of antibody to the virus, a presumptive clinical diagnosis of HTLV-III/LAV infection has been made in some situations in the absence of positive virologic or serologic test results. There is a very strong correlation between the clinical manifestations of AIDS as defined by CDC and the presence of HTLV-III/LAV antibody (11-14). Most persons whose clinical illness fulfills the CDC surveillance definition for AIDS will have been infected with the virus (12-14).

The web address for this article is:

http://www.cdc.gov/epo/mmwr/preview/mmwrhtml/00033651.htm

i A revision of the classification system was published in 1993 in 1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults, MMWR Recommendations and Reports, December 18, 1992 / 41(RR-17). The report can be found on-line at:

http://www.cdc.gov/mmwr//preview/mmwrhtml/00018871.htm

The current CDC HIV case definition is in the Appendix to the **MMWR** Recommendations and Reports article, "Guidelinesfor National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome," December 10, 1999 / 48 (RR13); 1-28.

This publication is available on-line at the CDC website at:

http://www.cdc.gov/mmwr//preview/mmwrhtml/rr4813a2.htm

One of the most crucial recent changes in the CDC HIV case definition was the addition as of January 1, 2000 of a positive HIV viral load test as defining HIV infection for the purposes of public health HIV case surveillance.

AIDS Case Definition: TDH uses the CDC case definition for AIDS. The earliest AIDS case definition was in the CDC article in *MMWR*, "Current Trends Update on Acquired Immune Deficiency Syndrome (AIDS) --United States," September 24, 1982 / 31(37); 507-508,513-514. In the publication CDC stated that:

"CDC defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease. Such diseases include KS, PCP, and serious OOL((S)) Diagnoses are considered to fit the case definition only if based on sufficiently reliable methods (generally histology or culture). However, this case definition may not include the full spectrum of AIDS manifestations, which may range from absence of symptoms (despite laboratory evidence of immune deficiency) to non-specific symptoms (e.g., fever, weight loss, generalized, persistent lymphadenopathy) (4) to specific diseases that are insufficiently predictive of cellular immunodeficiency to be included in incidence monitoring (e.g., tuberculosis, oral candidiasis, herpes zoster) to malignant neoplasms that cause, as well as result from, immunodeficiency((P)) (5). Conversely, some patients who are considered AIDS cases on the basis of diseases only moderately predictive of cellular immunodeficiency may not actually be immunodeficient and may not be part of the current epidemic. Absence of a reliable, inexpensive, widely available test for AIDS, however, may make the working case definition the best currently available for incidence monitoring."

i The web address for this document is: http://www.cdc.gov/mmwr//preview/mmwrhtml/00001163.htm

Other articles of interest concerning the AIDS case definition (and their web addresses, if available) are:

- i Current Trends: Revision of the Case Definition of Acquired Immunodeficiency Syndrome for National Reporting--United States, MMWR, June 28, 1985 / 34(25); 373-5 http://www.cdc.gov/mmwr//preview/mmwrhtml/00000567.htm
- i Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome, MMWR Supplements, 36, August 14, 1987 [suppl. no. 1S]: 1S-15S).

 No Web address currently available
- i 1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults, MMWR Recommendations and Reports, December 18, 1992 / 41(RR-17) http://www.cdc.gov/mmwr//preview/mmwrhtml/00018871.htm
- i Current Trends Update: Acquired Immunodeficiency Syndrome -- United States, 1994, MMWR, February 03, 1995 / 44(04); 64-67 http://www.cdc.gov/mmwr//preview/mmwrhtml/00035736.htm

The most sweeping change in the AIDS case definition came in 1993. At that time, not only were more AIDS indicator diseases added, but also anyone with documented HIV infection and a severely depressed CD4+ T-cell count became redefined as AIDS cases. This led to a certain amount of discontinuity in AIDS trend data over the years, with 1993 marking the start of a period when yearly AIDS cases show a distinct rise.

HIV/AIDS Surveillance

Anonymous HIV Reporting System: No attempt is made to distinguish one case from another. Often information such as age, sex, and race is collected.

Adult and Adolescent HIV Reporting By Name: Confirmed HIV infections in people age 13 or more have been reported by name since the January 1, 1999 as long as they had an HIV test done on or after that date.

CD4+ < 200: The CD4+ (or T-cell lymphocyte) count became an important part of the AIDS surveillance case definition that the CDC revised in 1993. The current AIDS case definition includes all HIV-infected persons with CD4+ counts fewer than 200/uL of blood or less than 14% of total lymphocytes. Before this change, the case definition relied on a confirmed positive HIV antibody test and the identification of one of several indicator diseases that commonly occur among immunocompromised HIV-infected patients. This change in definition resulted in a large number of AIDS cases being reported in 1993 that had not met the earlier case definition

Confidential HIV Reporting: A surveillance system for HIV infection that uses the names of individuals and protects them from disclosure.

HARS: HIV/AIDS Reporting System, a CDC-sponsored software used by TDH for data collection of HIV and AIDS cases.

Living HIV and AIDS Cases: Tabulations of persons living with HIV infection and AIDS include all persons for whom no date of death is carried on the HARS database.

Pediatric HIV Reporting By Name: Confirmed HIV infections in children 12 years of age and younger have been reported by name since 1994.

Progression to AIDS: Persons with HIV infection may be tested at any point in the clinical spectrum of disease; therefore, the time between diagnosis of HIV infection and AIDS will vary. In addition, because surveillance practices differ, reporting and updating of clinical and vital status of cases vary among states.

Reporting Delay: Time between diagnosis of HIV infection or AIDS and report as a case to TDH. Reporting delays may vary among exposure, geographic, racial/ethnic, age, and sex categories.

Retroactive Reporting: A surveillance system <u>can</u> be developed to intentionally ask for reports on cases occurring prior to the start date of a reporting system or prior to the implementation of a rule change – this would constitute retroactive reporting. TDH specifically said that <u>under the 1999 HIV case definition</u>, it would neither seek nor accept HIV tests done before the January 1, 1999 start date. So, all HIV cases included in this analysis had some evidence of HIV infection wherein the qualifying date was on or after January 1, 1999. However, when the year 2000 CDC HIV case definition was published, it included viral load reporting. TDH reporting rules adopt the CDC case definitions by reference. So, for viral load tests done on or after January 1, 2000, all non-zero or positive HIV viral load tests became accepted as defining an HIV case. Because viral load testing, unlike antibody testing, is done on a routine basis for people at many different stages of HIV disease and AIDS, this introduces an element of retroactive reporting to the surveillance system by capturing data on cases that got HIV antibody tests earlier.

Unique Identifier (UI) HIV reporting. Reporting of confirmed HIV infections by unique identifier (UI) for adolescents and adults began in March, 1994 and was discontinued as of January 1, 1999 when confidential named reporting was begun in Texas. The UI reporting system in Texas was a dual system, with both test providers and laboratories required to report the four pieces of information of the UI for each individual with a confirmed HIV infection:

- i the last four digits of the social security number (SSN)
- i month, day, and year of birth (DOB)
- i a numeric code for sex
- i a numeric code for race/ethnicity

These elements were chosen because, in theory, they are enduringly and consistently associated with each person. Mathematical modeling has demonstrated that combinations of these four elements usually allow true unique identification of an individual's report, and thus allow detection of duplicate reports. In addition to the UI information, test type, test date, test result, the zip code, city, and county of residence of the infected individual, and

the name and address of the provider/laboratory reporting the infection is also required. No information on risk behaviors was routinely collected on HIV reports.

A three-and-a-half year evaluation of this surveillance system indicated that the reporting mechanism led to information that was incomplete and possibly biased. Completeness of the data elements needed to construct the UI stood at only 44%, completeness of reporting thus was insufficient, with 25% to 60% of the actual HIV infections diagnosed in the years between 1994-1997 reported. Further, the system tended to have a distinct bias towards collecting data from public

reporting sources and not from private sources (__ to __%), and little risk information was obtained.

The system was a *unifunctional* system, at best capable of providing only information for epidemiologic monitoring of HIV infection, and unable to systemically support patient referral and disease intervention services. This shortcoming was recognized but not resolved at the time of the system's design. Moreover, because of the difficulty in following back incomplete infection reports using only a UI: further investigation to get missing elements or to obtain risk information was not feasible.

Viral Load HIV Reporting: In recent years, medical researchers have developed tests that quantify the level of HIV virus circulating in the bloodstream. These tests are referred to as viral load or plasma HIV (RNA) tests. Viral load tests are a sensitive measure of the HIV nucleic acid in the peripheral blood and other body systems In January 2000, the Texas Department of Health began mandatory Viral Load reporting for HIV and AIDS cases. This occurred because the surveillance case definition for HIV was updated by the CDC in December of 1999, to include a detectable viral load as an independent criterion for HIV infection and the HIV reporting law in Texas uses the CDC HIV case definition. Texas implemented the reporting of viral load results on January 1, 2000 and these data, in conjunction with the new HIV (not AIDS) reports will eventually provide prevalence data on HIV cases in the State of Texas (all existing cases).

Notes on Dates

Database Updated Through (Date): Includes information received by TDH and entered into the HARS system through the last day of the date stated.

Date of Diagnosis: For AIDS, the month, day, and year the case was diagnosed with AIDS (using the CDC case definition). For HIV, the month, day and year the case was first found to be HIV-positive on an HIV test.

Date of Report: The month, day, and year the case was entered into the HARS data collection software system. Data entry is done both by local or regional surveillance staff and by staff at the Austin central office. This means that there can be cases with a date of report, say in March, that do not actually become a part of the central office HARS registry, until say, April.

Date of Death: The month, day, and year the case died. This date is usually obtained from the TDH Bureau of Vital Statistics death certificate.

First *Known* HIV Positive Test Date: This is NOT the same as the qualifying date for the test that resulted in it's reporting to TDH. Once a test is done **on or after January 1, 1999**, surveillance personnel investigate medical records to try to ascertain the person's earliest test in which they were

found to be infected with HIV.

Date of Birth: The month, day, and year the case was born. This date is used to calculate the age at diagnosis.

Notes on Demographics

Age: Data are collected by single years of age, although breakdowns by months of age for children under the age of one are also often available. Tabulations are based on the person's age at first documented positive HIV- test for HIV infection cases, and age at diagnosis of AIDS for AIDS cases. Adult/adolescent cases include persons 13 years of age and older; pediatric cases include children under 13 years of age. The most commonly used age groups other than these two broad categories are: <1 year of age, 1-12, 13-19, 20-24, 25-29, 30-39, 40-49, 50-59, and age 60 or older. It should be noted that in most presentations, graphic or tabular, age refers to "age at diagnosis". However, because we do collect date of birth, it is also possible to calculate a case's *current age*.

Race/Ethnicity: TDH currently uses the formal race/ethnicity designations, that appear on the CDC form for HIV/AIDS cases. However, most HIV/AIDS case reports are taken from medical records. Providers design their own medical records and it is unlikely that they do so with the CDC HIV/AIDS race/ethnicity categories in the forefront of their minds. Further, staff of these medical reporting sources actually may assign a patient to a category based on what the person says about themselves concerning race/ethnicity; it is also possible that medical personnel make the assignment of race/ethnicity themselves based on the patient's appearance or surname.

White (not Hispanic): All Whites who are not also Hispanics. Excludes Blacks/African Americans, American Indians, Alaskan Natives, Asians, or Pacific Islanders.

Black/African American (not Hispanic). All Blacks/African Americans who are not also Hispanic. Excludes Hispanics, White non-Hispanics, American Indians, Alaskan Natives, Asians, or Pacific Islanders.

Hispanic: All Hispanics of any race.

American Indian or Alaskan Native: All American Indians or Alaskan Natives who are not also Hispanics. Excludes White non-Hispanics, Hispanics, African Americans, Asians, or Pacific Islanders.

Asian or Pacific Islander All Asians or Pacific Islanders who are not also Hispanics. Excludes White non-Hispanics, Hispanics, African Americans, American Indians, and Alaskan Natives.

Not specified: No race/ethnicity given.

When presenting tables, graphics, and reports on HIV and AIDS, TDH often collapses numbers from the latter three race/ethnicity categories into the designation *Other*. If there are considerable numbers of cases in the *Not Specified* category, however, this designation is not included under *Other* and instead remains *Not Specified*.

Sex: The CDC HIV/AIDS Surveillance reporting form includes two, mutually exclusive, categories for designating the sex of the case: *Male* and *Female*. Categorization into one or the other is based upon the person's sex at birth, not their sex at the time of diagnosis or report.

Notes on Geography

HARS Reporting Site: The local or regional health department location where reports of HIV or AIDS are collected from reporting sources such as laboratories, medical providers, and hospitals, among others. This reporting site usually enters cases into the HARS software before sending data electronically to the TDH HIV/AIDS surveillance central office. Local and Regional Health Departments are on the front line of HIV/AIDS reporting activities. A city, county, or regional health department is responsible for HIV/AIDS case data collection from reporting sources that are located in certain geographic areas; these areas diverge sharply in geographic size and/or population size. Some HARS areas with high morbidity have funded positions to work on HIV/AIDS surveillance activities. Others report a considerable number of cases on a regular basis but do not have positions dedicated solely to HIV/AIDS surveillance activities.

Residence County: Refers to the county in which the case was living at the time of diagnosis with HIV or AIDS.

Public Health Region: TDH maintains both a Central Office in Austin and 11 TDH Regional Offices that serve specific counties. When we tabulate HIV or AIDS cases by Public Health Region of residence, we add the numbers from those counties together to get the total for the region. This is based on the residence county of the case.

State of Residence: Reportable conditions diagnosed in residents of other states in the US, while they are visiting Texas, are reported to the health authorities of the individual's home state. These cases <u>are not</u> included in this report. Reports regarding Texas residents who became ill while visiting other states <u>are</u> included in this report

Texas Department of Criminal Justice (TDCJ): Refers to the residence area used for both HIV and AIDS cases diagnosed while a person is incarcerated in one of the Texas state prison facilities. These cases are not assigned to the county in which they are incarcerated or to the county in which they last resided, but are assigned to a special residence category (TDCJ) that denotes diagnosis while in prison. The reason for this is to give better statistics for counties—if prisoners were counted as residing in the county in which the prison facility is located, a few counties would have unreasonably high numbers and rates of HIV/AIDS.

Epidemiologic/Statistical Notes

Adjusted for delays in reporting: Particularly when presenting tables or graphs of HIV or AIDS by date of diagnosis, both Texas and CDC often adjust these data to project how many cases there would be if all that were going to be reported had already come in to TDH. When we do this, Texas usually uses its own method of adjusting for reporting delay, not the method used by CDC. The TDH method, although it differs in details, is similar to the CDC method in that it projects the number of cases to be diagnosed eventually in a year using historical statistical data on the lag-time between diagnosis with AIDS or HIV and the report of past cases to TDH. Abrupt departures from historical trends in lag-times have been noted in AIDS cases reported since the beginning of 1999, with the interval suddenly becoming shorter, on average. This means that the algorithm for adjusting must be revised.

HIV (not AIDS): An HIV case not yet reported as an AIDS case. In these analyses, when we speak of HIV cases, we mean those people reported with HIV who had *not* progressed to AIDS by the end of the year. This makes the two categories (AIDS and HIV) mutually exclusive. Over time, persons with HIV infection will be diagnosed and reported with AIDS. HIV infection cases later reported with AIDS are deleted from the HIV infection tables and added to the AIDS tables.

Interpretation of AIDS Reporting Information: AIDS cases have always represented people with late-stage HIV disease; however, with the advent of new anti-viral therapies, which became generally available in mid-1996, AIDS cases increasingly are becoming representative of a sub-population of people with HIV who either did not receive the therapy or who did receive the therapy but are, for one reason or another, considered to be treatment failures. Those who get the drugs and respond to them often do not reach the late-stages of HIV disease and thus they are not reported as AIDS cases and are not included in the count of AIDS cases. So the character of AIDS cases has changed somewhat since 1996.

Interpretation of HIV Infection Reporting by Name Information. HIV surveillance reports may not be representative of all persons infected with HIV since not all infected persons have been tested. Texas offers public sector anonymous HIV testing and commercial home

collection HIV test kits are available. Anonymous test results are not reported to the confidential name-based HIV registry. Therefore, confidential HIV infection reports may not represent all persons testing positive for HIV infection. Furthermore, many factors may influence testing patterns, including the extent to which testing is targeted or routinely offered to specific groups and the availability of and access to medical care and testing services. In tandem with AIDS cases, these data provide a minimum estimate of the number of persons known to be HIV- infected.

Rates: Rates are calculated using HIV and AIDS cases reported in the calendar year 1999 and population estimates for 1999 from the Texas State Data Center; they are expressed as cases per 100, 000 population.

Population Counts and Estimates: The population data used in this report represent projections for 1999 from the Texas State Data Center, Texas A&M University.

Mode of Exposure to HIV

Risk Behaviors, (after 1977 and preceding the first positive HIV antibody test): The HIV/AIDS Confidential Case Report Form collects information on the following risks. There are check boxes beside each risk for "Yes", "No", and "Unknown" responses. Most of the risk information TDH collects comes from medical records, not from personal interviews with patients. Note that because the gender of the case is known, it becomes possible with this information to conclude whether the case engaged in male-to-male sex or female-to female sex. However, note also that female-to-female-sex is not, in and of itself, considered to be a transmission risk for HIV.

- i Sex with male
- i Sex with female
- i Injected nonprescription drugs
- i Received clotting factor for hemophilia/coagulation disorder
- i Heterosexual relations with intravenous/injection drug user
- i Heterosexual relations with bisexual male
- i Heterosexual relations with person with hemophilia coagulation disorder
- i Heterosexual relations with transfusion recipient with documented HIV infection
- i Heterosexual relations with Transplant recipient with documented HIV infection

- i Heterosexual relations with person with AIDS or documented HIV infection, risk not specified
- i Received transfusion of blood or blood components other than clotting factor
- i Received transplant of tissue/organs or artificial insemination
- i Worked in a health care or clinical laboratory setting

Exposure categories: For surveillance purposes, HIV infection cases and AIDS cases are counted only once in a hierarchy of exposure categories. Persons with more than one reported behavioral risk to HIV are classified in the exposure category listed first in the hierarchy. The priorities of the hierarchy are based upon CDC-calculated probabilities of HIV transmission during one episode of the behavior.

MSM-IDU: Men with both a history of sexual contact with other men and injecting drug use. They make up a separate exposure category.

MSM: Men who have sex with men cases include men who report sexual contact with other men (i.e., homosexual contact) and men who report sexual contact with both men and women (i.e., bisexual contact).

IDU: All persons who have injected non-prescribed drugs, even once, since 1977.

Heterosexual contact: cases are in persons who report specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injecting drug user). This is a limited exposure category—it does not include most heterosexual encounters. For example, heterosexual sex with a sex worker does not automatically put a person in this mode of exposure; instead the sex worker must be known to have one of the behaviors risks listed above.

NIR: No Identified Risk Reported. Cases with no reported history of exposure to HIV through any of the modes considered by CDC to be behavioral risk categories leading to transmission. NIR cases include persons who are currently under investigation by local health department officials; persons whose exposure history is incomplete because they died, declined to be interviewed, or were lost to follow up; and persons who were interviewed or for whom other follow-up information was available and no exposure mode was identified. Persons who have an exposure mode identified at the time of follow-up are reclassified into the appropriate exposure category. Historically, investigations and follow up for modes of exposure by state health departments were conducted routinely for persons reported with AIDS and as resources allowed for persons reported with HIV infection. Therefore, the percentage of HIV infected persons

with risk not reported or identified is substantially higher than for those reported with AIDS. Recently reported cases are more likely to be categorized as NIR, but after sufficient time for field investigation, many of these NIR cases are re-distributed.

Blood or Blood Products: We often combine cases with hemophilia or transfusion exposures into one category. However, depending upon the situation, we may also leave them separated into:

Transfusion Recipient: Persons who have received blood via transfusions since 1978.

Hemophiliac: Persons who have received blood via transfusions since 1978 for the treatment of hemophilia or who have received factor concentrate since 1978 for the treatment of hemophilia.